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ABSTRACT

The participant's manual contains training materials for a national conference on cultivating media relations in agencies concerned with independent living for people with disabilities. Preliminary materials include the conference agenda, background information about the trainers, organizational information on Independent Living Research Utilization and the National Council on Independent Living, and conference learning objectives. The first section contains handouts including a media checklist, tips for getting coverage, basics of writing a press release, the press release layout (on agency letterhead), and guidelines for writing an op-ed piece. The bulk of the document consists of a reprint titled "ImPRESSive: Media Tip Sheets for Advocates." Sections of this publication address the following: building and maintaining relationships with reporters; creating working media lists; on the record and off the record (controlling the story); how to shift focus on a story; tips for interviews (newspaper); tips for interviews (radio); tips for interviews (television); and getting your message into national stories. The manual provides examples of newspaper articles written by various disability advocacy agencies and a detailed example of press coverage of a disability issue in one community. Visuals for a PowerPoint presentation complete the manual. (DB)

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IL NET Presents…

ED 479 820

Making News:
How the IL Movement Cultivates Media Relationships

October 16-18, 2002
Oklahoma City, OK

EC 309756

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Expanding the Power of the Independent Living Movement

IL NET
an ILRU/NCIL National Training and Technical Assistance Project

Expanding the Power of the Independent Living Movement

MAKING NEWS: HOW THE IL MOVEMENT CULTIVATES MEDIA RELATIONSHIPS

A National Conference

Participant's Manual

October 16-18, 2002
Oklahoma City, OK

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Making News: How the IL Movement Cultivates Media Relationships
A National Conference

Participant's Manual
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MAKING NEWS:
HOW THE IL MOVEMENT
CULTIVATES MEDIA RELATIONSHIPS

Agenda

Wed., Oct. 16

8:30 Continental Breakfast

9:00 – 9:20 Introductions

Shifting the Paradigm from Medical Model to Civil Rights/Independent Living

9:20–10:30 Motivational Panel Discussion

- Changing attitudes
- Being the "source" or media spokesperson.
- Discussion about language.

10:30-10:45 Break

Developing the Message

10:45-11:15 Large Group Exercise – Developing the Message

- What is the IL philosophy, according to the group.
- What's your measuring stick? True to purpose?

11:15-12:15 Small Group Exercise (to develop the message)

12:15 – 1:45 Lunch on Your Own

Working with the Media

1:45 – 2:15 Overview of Media. The different types of media, how they work, what works best for what type of activity.

- Wall between editorial and news desk/reporters
- Print media
- Broadcast media
- Electronic media

2:15 – 3:15 The Press Release
- How to use a press release effectively
- How the newsroom works.

3:15 – 3:30 Break

3:30 – 4:40 Exercise - Develop an angle to pitch to local reporter, letter to editor, piggy-back to make news locally. Report back to large group.

4:40 – 5:00 Making media advocacy a part of your daily work.
- What is media advocacy?
- A SILC Model

Homework. Pick up newspaper, watch News tonight. Any stories that can be used to pitch the disability rights message?

Thurs., Oct. 17

8:30 Continental Breakfast

9:00 – 9:15 Review of concepts learned in first day.
Check homework, discuss possible issues.

Keys to Building Relationships

9:15 – 10:45 Exercises: Role Plays for Building a Relationship and Dealing with an "on-the-spot" situation

10:45 –11:00 Break

11:00-12:00 Media Panel from Norman, Oklahoma (t.v., radio, newspaper)
- Pam Henry, former Supervisor of News Room for PBS Station OETA, Oklahoma City, OK
- Patrick McGuigan, former Managing Editor, Daily Oklahoman, Oklahoma City, OK
- Heather Spencer, Morning and Evening News Anchor, NPR radio, Norman, OK

12:00-1:30 Lunch on Your Own

Developing a Media Plan

1:30 - 2:15	The Editors. Who are they and what is their role, different types of editors, how can we work with them? • Letter to the editor/value of letter to editor campaign • The op-ed • The editorial board visit • Deciding frequency of contact
2:15 – 2:30	Planning an effective Press conference
2:30 – 3:15	The Media Plan. What it is and how it benefits your organization.
3:15 – 3:30	Break
3:30 – 5:00	Exercise: Creating a media plan. Small group Report back.

Fri., Oct. 18

8:30	Continental Breakfast
9:00 – 9:15	Review of Where We Are

Developing and/or Using Existing Marketing Campaigns

9:15 – 10:30	An Example – the TRIPIL Campaign • ad examples • attitude shifts • marketing their services NCIL Media Kit • what it is • how it was developed
10:30-10:45	Break
10:45-11:50	The Corporate Connection AT&T Broadband AAPD & Torch Rally
11:50-12:00	Wrap-Up

ABOUT THE TRAINERS

Jennifer Burnett has been involved in the disability rights movement since 1992. She is currently Project Director of PA Transition to Home, a nursing home transition project, and coordinates the Power statewide conferences in Pennsylvania and Maryland, designed to empower people with disabilities. Jennifer has developed and promoted a training curriculum to promote the disability rights message at the grassroots level. She is committed to working with the disability community to incorporate and develop advocacy strategies, which use the media as a tool for changing attitudes towards disability and understanding of the disability experience by the general public. The training modules can be used and adjusted to meet the needs of the sponsoring organizations, and trainings have ranged from an hour and a half to two days. The training has been sponsored by AAPD, PA and MD SILC, TASH, ADAPT, and numerous other smaller organizations.

Burnett is a frequent contributor to **MOUTH** and **Ragged Edge** magazines, and writes a **Ragged Edge** column called the "Media Edge."

Janine Bertram Kemp is the President of Cedar Media, LLC, a communications and media training firm. She was formerly Chairman of the Board of Evan Kemp Associates, a retail outlet for rehabilitation and transportation products. Prior to joining the business world, she spent over twenty years as a consultant and community builder in the disability rights and prison reform movements. She is President of the board of the Disability Rights Center and also serves on the board of the National Spinal Cord Injury Association. She has been a member of Not Dead Yet since its inception, and is proud to be one of the founding members of Capital area ADAPT.

Brad Williams is the executive director of the New York Statewide Independent Living Council. Previously he held the position of executive director of the Glens Falls Independent Living Center for nine years. Brad has extensive experience in coordinating media campaigns for systems advocacy, including a four-month campaign with the New York State Attorney General's Office to support a Federal District Court decision mandating that each county needs to ensure the full accessibility of polling places; a two-year campaign to obtain a Medicaid buy-in for New Yorkers with disabilities; and a two-month campaign to force a reversal of a building code decision that would have severely limited the new accessible housing stock. He is currently involved in a six-month campaign to enact state legislation that will ensure that New York complies with the 1999 Olmstead U.S. Supreme Court decision.

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ABOUT ILRU

The Independent Living Research Utilization (ILRU) Program was established in 1977 to serve as a national center for information, training, research, and technical assistance for independent living. In the mid-1980's, it began conducting management training programs for executive directors and middle managers of independent living centers in the U.S.

ILRU has developed an extensive set of resource materials on various aspects of independent living, including a comprehensive directory of programs providing independent living services in the U.S. and Canada.

ILRU is a program of TIRR, a nationally recognized, free-standing rehabilitation facility for persons with physical disabilities. TIRR is part of TIRR Systems, a not-for-profit corporation dedicated to providing a continuum of services to individuals with disabilities. Since 1959, TIRR has provided patient care, education, and research to promote the integration of people with physical and cognitive disabilities into all aspects of community living.

ABOUT NCIL

Founded in 1982, the National Council on Independent Living is a membership organization representing independent living centers and individuals with disabilities. NCIL has been instrumental in efforts to standardize requirements for consumer control in management and delivery of services provided through federally-funded independent living centers.

Until 1992, NCIL's efforts to foster consumer control and direction in independent living services through changes in federal legislation and regulations were coordinated through an extensive network and involvement of volunteers from independent living centers and other organizations around the country. Since 1992, NCIL has had a national office in Arlington, Virginia, just minutes by subway or car from the major centers of government in Washington, D.C. While NCIL continues to rely on the commitment and dedication of volunteers from around the country, the establishment of a national office with staff and other resources has strengthened its capacity to serve as the voice for independent living in matters of critical importance in eliminating discrimination and unequal treatment based on disability.

Today, NCIL is a strong voice for independent living in our nation's capital. With your participation, NCIL can deliver the message of independent living to even more people who are charged with the important responsibility of making laws and creating programs designed to assure equal rights for all.

ABOUT THE IL NET

This training program is sponsored by the IL NET, a collaborative project of the Independent Living Research Utilization (ILRU) of Houston and the National Council on Independent Living (NCIL).

The IL NET is a national training and technical assistance project working to strengthen the independent living movement by supporting Centers for Independent Living (CILs) and Statewide Independent Living Councils (SILCs).

IL NET activities include workshops, national teleconferences, technical assistance, on-line information, training materials, fact sheets, and other resource materials on operating, managing, and evaluating centers and SILCs.

The mission of the IL NET is to assist in building strong and effective CILs and SILCs which are led and staffed by people who practice the independent living philosophy.

The IL NET operates with these objectives:

- Assist CILs and SILCs in managing effective organizations by providing a continuum of information, training, and technical assistance.
- Assist CILs and SILCs to become strong community advocates/change agents by providing a continuum of information, training, and technical assistance.
- Assist CILs and SILCs to develop strong, consumer-responsive services by providing a continuum of information, training, and technical assistance.

MAKING NEWS:
HOW THE IL MOVEMENT CULTIVATES MEDIA RELATIONSHIPS

Learning Objectives

Participants will be able to:

1. Gain comfort in speaking to media representatives;
2. Acquire tools to develop a media plan in your organization;
3. Learn how to use the power of the media to change attitudes and strengthen advocacy efforts; and
4. Develop skills in creating a message and a marketing campaign.

Media Checklist

Local

- ☐ If the event is planned and announced in advance, send out a media advisory. This is a very simple one page description of the event, with a listing of who, what, where, when, why. This should be sent out at least one week in advance of the event, so that the media is aware of it and has it in the schedule. May be helpful to talk to the daybook editor in larger outlets, encouraging them to list it.

- ☐ Create a press release explaining what the event is about including contact name and number. Include in press kit and/or FAX out to local media contacts.

- ☐ Assemble press kit. Collect background/supporting information to be included in press kit. Statistics (including source) and relevant newspaper clippings are very useful. Information on your organization, as well as the issue, should always be included. Don't forget the press release.

- ☐ Maintain a Media Contact list. Make sure it is updated, with accurate telephone numbers, FAX numbers, and contact person. Call individual media contacts, including local print media, television and radio the day before the event gets underway. If possible, pitch the story to media contacts a few days before event.

- ☐ Assign someone to be onsite media contact. They should have cell phone, which should be listed on the press release. They should be on lookout for media "types", and greet them with press kit and offer assistance if needed.

- ☐ Follow-up. FAX out "result of event" press release to local media, and if possible E-mail .

- ☐ Clip and save any coverage you get. If possible, follow up coverage with a call or letter to the reporter thanking him, and inviting him to meet with your group to give him/her the exclusive, full story!!

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Tips for Getting Coverage

1. **Develop and maintain a media List.** The list should include all personal contacts you've made, reporters who have covered our issues/actions, as well as general contacts. For print media, include news reporters and editors. Television (local, cable, and network,) radio, daily newspapers, weekly newspapers, ethnic newspapers, student newspapers, neighborhood, union and religious publications. Include relevant information for all contacts: Contact name, publication, address, telephone and FAX number, and e-mail address.

➔ *In dealing with the daily or weekly newspaper, it is definitely worth your time to cultivate a relationship. They are always looking for newsworthy information, and your organization is it. Develop a reputation for being reliable and expert.*

2. **Think pictures.** When press coverage is likely, think pictures. Notify the press that there will be "photo opportunities", increases likelihood of media coverage. Take your own pictures and make them available to press, either by contacting in person or on press release. Signs, props, and visuals all increase photo opportunities.

3. **FAX press releases.** The object of the press release is to get media to cover action or other event, or write a story on your issue. Keep it simple, but remember basics: Accurate contact information, who, what, when, where, why are you issuing the release. Use terms you are familiar with and write in a style you are comfortable with. Consider the release a "hook" to get media there.

4. **Follow up press releases with calls.** No matter how good your press release is, you'll have a better chance of being covered if you follow up with a phone call. If the release is not going to a specific person, there's a good chance it went nowhere, or to the "wrong" person.

5. **Respond to any coverage of disability issues.** If there is a story in your newspaper about a "wonderful nursing home", send a response to letters to the editor. Better yet, make contact with the reporter, thank him for covering this issue, and give him the real scoop on nursing homes.

Press Release Basics

1. A press release is not the message. The action or event is the message. The press release is an advertisement to get the media to cover the event. The first two paragraphs are far more important than the rest of the release, and the headline is the most important.

2. The first sentence should capture the reader, and give them a reason to be interested in the event. It should be no more than 37 words and tell who, what, where, when, why.

3. In the following paragraphs, provide the details of who, what, why, where, and when (including street address and time of event.)

4. The release should be on one page only, using letterhead, which identifies the organization and an address and telephone number. If it does go to two pages use -more- at the bottom of page one, and ### at the end of every release.

5. Use clear language that explains the issue, reason for event, and demonstrates why it is newsworthy. Local press picks up readily on local interests.

6. At least one quote from an individual with standing should be included in the body of the release. The quote should emphasize and "sell" the event or action. The individual quoted should not be the individual identified as the contact on the release.

7. The contact person on the release must be available by phone, to speak with media who respond.

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Press release layout, on letterhead

FOR IMMEDIATE RELEASE	For more information call:
Date:	Contact name(s):
	Numbers, inc. cell phone that works

HEADLINE, IN CAPS

YOUR TOWN, STATE—First sentence sells the reader, tells your story in a "nutshell." This first sentence should not exceed 37 words. Reporters may ask for the "story in a nut"

Next 3-4 paragraphs, give details. Who, what, where, when, why (including why this is important.) Keep it clear and concise, no extra words just to fill white space! A quote is a good selling point, particularly if it comes from a known entity, a person with "standing."

If more than one page, be sure to put –more-- at the bottom of the first page, and an identifier at the very top of second page, including "page 2." Look at your spacing, and use 1.5 spacing between lines if you can, as this is easier to read.

Finish with ###

Write an Op-Ed

GETTING STARTED

1. **Research. Look at the editorial pages** of your local newspaper for several days to get an idea of how it covers opinion (op-ed) material. Besides "letters to the editor," there are columns written by readers, like "In My Opinion," or "Commentary." Read lots of op-eds to see how they're constructed. It may help to notice style, content, tone, and incorporate this into your own piece. Remember, this is OPINION, but an editor makes the decision to run it.

2. **Call the newspaper.** The number is listed in the newspaper, or you can always get it out of the phone book. Ask to be connected with someone who can answer questions about their editorial policy towards submitting op-ed material. Once you reach the person with accurate information, ask questions about how to submit an op-ed: how many words, what format, timeframes, how to submit (fax, e-mail, or hard copy by mail, etc.) Get the opinion page editors name (correct spelling) and contact information so you can send your article directly to him/her.

WRITING YOUR COMMENTARY

3. **Write the body of your op-ed piece now.** Op-eds are generally about 750 words, so you should prepare a piece of about 600 words as a first draft. This will be the body of your op-ed. If the op-ed is newsworthy right now, get it in immediately. However, you might think about preparing a piece long before it is timely or newsworthy. For example, in advance of an ADA or IDEA anniversary, or in anticipation of an event you are sponsoring. If you prepare the op-ed piece well in advance, you can fine tune it and have it ready to go when something newsworthy happens related to the issue you've written about.

4. **Tie your op-ed to a good "news hook"** related to breaking news, whenever possible. Your op-ed should be slated to run on or near the date of something newsworthy. For example, an ADA Supreme Court challenge, an event sponsored by a disability organization, or even direct action.

5. **The op-ed editor must realize this is BIG NEWS**. Be sure to have information that shows this is a big news story, use articles that have appeared over the past few months (called clips.) Use this "news hook" and lead your op-ed with that. Express your point of view clearly and boldly in the first paragraph. If you have the body written already, you can just add the "hook" when you are ready to get it to get it to the editor. That way, you can do it quick. And quick is essential.

POINTERS FOR GETTING PUBLISHED

1. **Timeliness.** You MUST get your op-ed into the editor in time for it to be newsworthy. It WILL NOT get published unless you strictly adhere to the editor's guidelines, and get it in by any deadline he/she may establish.

2. **What editors want is:**
   a) Timeliness: Newsworthy and meets deadlines
   b) A well-stated point-of-view with a topical beginning hooked to the news.
   c) The view of someone with "standing." Standing means that you are an authority on this issue. Examples: "Parent who has battled his child's school district," or "Self-advocate who has escaped from a developmental center." If you are on a board or are appointed to a council, and can demonstrate your authority, play it up!
   d) The correct length.

3. **Keep it Simple.** Boil your argument down to three major points. Use simple, short sentences. Avoid fancy words and jargon, acronyms. Make your paragraphs short—no more than three sentences each.

4. **Power Ending.** Close on a strong note. A short, powerful last paragraph should drive your point home. And get ready to move your opinion piece the moment *big news* happens.

Special thanks to Bill Stothers and Mary Johnson.
Center for an Accessible Society
A version of this information ran in the May/June 1999 Ragged Edge.

For more information, contact The Media Advocacy Project
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ImPRESSive

Media Tip Sheets for Advocates

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ImPRESSive

A MEDIA TIP SHEET FOR ADVOCATES
Families USA ı April 2002

Building and Maintaining Relationships with Reporters

Building and maintaining relationships with reporters are essential to getting your message out to the press. Having strong relationships with reporters helps position your organization on the front line and allows you to get your message into health care stories seamlessly. If you want reporters to contact you for comments, or if you would like to draw reporters' attention to neglected health care issues, a well-developed rapport will enable you to do so. An equally important part of this equation is maintaining your relationships with these reporters over time; building and maintaining these relationships are essential to press outreach.

BUILDING THE RELATIONSHIP

1. SEND A PACKET OF INFORMATION

The first step in building relationships with reporters is sending them an information packet. This keeps you from having to "cold call" reporters and also allows them to have your contact information handy. This packet should include a brief one-page write-up about your organization, some articles mentioning your organization, and your contact information. In addition, if your organization has resources such as reports, include these as well. This packet should demonstrate how your organization could be a resource to these reporters.

To whom do you send the information packet? If your organization has a press list, this is a good place to start. Otherwise, if you are starting from scratch, you may want to take the time to create a working press list or a list of reporters who cover health care stories in your local papers. For more information on how to create a solid press list, please see our past *ImPRESSive* entitled "Creating Working Media Lists."

2. INTRODUCE YOURSELF

After you have sent the packet of information, give each reporter a follow-up call. The information packet serves as a good excuse for making this call. You can start off the conversations by introducing yourself and asking if they received your information packet.

Because reporters never have very much time, make this call short. Briefly explain who you are and what your organization does. This should all be explained in the context of how your organization can be a resource to them. Let them know that they can call you at any time if they have any health-related questions and that you would be happy to talk to them about health care issues. In addition, let them know about any upcoming press events you may be having. End the conversations by asking them if it would be okay for you to call them once a month to check in and tell them what is going on in the health care world. A simple, short call is all you need to start a relationship with a reporter.

To prepare for the calls, organize your information ahead of time: Have helpful documents such as talking points in front of you during the call. A reporter's first impression of you should be that you are knowledgeable and that you will be a good resource.

At the end of the conversations, make sure to collect their contact information. E-mail is a great way to communicate directly with reporters, since faxes often get lost or are delivered to the wrong person. In addition, make sure you have their correct fax and phone numbers.

Another great way to meet reporters is to make a point of introducing yourself to them at press events. This not only is a good way to add new people to your existing press list, but it also allows them to put a face to your name. Introduce yourself, give them a *brief* description of what your organization does, give them your card, and let them know that you can answer any health care related questions they may have.

3. MEET FOR LUNCH OR COFFEE

There are some key reporters with whom you may want to foster a closer relationship. If you live in a small media market, this may mean all your health beat reporters. If you have a long list of reporters on your press list, you may want to single out a couple of key reporters. Research news clips to find out which reporters are writing regularly on your issue. Identify reporters with whom you would like to have a closer relationship, and, during your follow-up call, ask them if they would like to go out to lunch or to coffee with you. Explain that you would like to talk to them about upcoming events, legislative actions, and the latest trends in health care. Take a press kit, even if you have already sent one to them. If you have any new news articles, add those to the existing press kit. Be prepared to talk briefly about

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how your organization can be a resource to that reporter. Make sure you keep your conversation professional, and remember that nothing you are saying is off the record. Keep the conversation away from anything controversial that you would not want the reporter to print the next day. In addition, don't take over the conversation. This is also a good time for reporters to ask any health care questions they may have and to share what issues they have a particular interest in.

Most reporters are not allowed to accept "gifts"; therefore, they will most likely pay for lunch. However, be prepared in case they split the tab or in the unlikely event that they let you pay the bill.

Sample
Introduction call
to a Reporter

Hi, may I speak to Sally Quinn.

Hi, Sally, my name is Joanne Peters, from Health Care Today. I sent you a packet of information on our organization last week and I wanted to call and make sure you received it and to see if you had any questions.

I also wanted to let you know about our upcoming press event on the uninsured.

Our organization focuses on... So please call me if you have any questions regarding these issues. I would be happy to add you to our e-mail list.

What to Say and Bring to your Lunch or Coffee with Reporters

☑ ***DO*** bring a press packet with information on your organization and current reports, issue briefs, press releases, and fact sheets.

☑ ***DO*** bring your business card and/or include contact information in your press packet.

☒ ***DON'T*** take over the conversation. This is a time for you to build relationships with these reporters—not to impress them with your knowledge of the issues.

☑ ***DO*** allow the reporters to ask questions. This is their time to explore the issues and sometimes pose the dumb questions they have always wanted to ask.

What to Include in your Press Kit

- ✓ Fact sheet on the issue
- ✓ Clips of previous articles about your organization (2-5 articles)
- ✓ Business card or contact information for your organization's main press contact
- ✓ Information on your organization (1 page)

MAINTAINING THE RELATIONSHIP

Maintaining strong relationships with reporters requires a great deal of follow-up, but the long-term benefits are unlimited. As soon as you establish yourself as an accurate, timely, and informative resource, you will have no trouble maintaining these relationships.

ESTABLISH YOURSELF AND YOUR ORGANIZATION AS A RESOURCE FOR THE REPORTER

In order to establish your organization as a credible resource, the most important thing to remember is to get the right information to them as quickly as possible.

Whenever a reporter calls you, take the request, ask about the deadline, and get the request answered in that time frame. Reporters often call at the last minute, and if you are able to get the information to them quickly, they will keep your name in their Rolodex for life. Your organization may want to create a Media Call Sheet where you record all the important information, such as the reporter's name, affiliation, contact information, request, and deadline. Through these tracking sheets, you can make sure to collect the right information and to answer the reporter's request in an appropriate and timely fashion.

In addition, it is always a good idea to keep a database of these reporter requests. This will allow your organization to track what specific reporters are writing about and how often your organization works with them.

Sometimes reporters will call and ask you things that don't fit into your organization's framework. Whenever possible, try to get them the information they need—even if that information is a referral to another organization or another organization's phone number. For example, if a reporter calls and says she is writing a story on senior citizens and the high cost of prescription drugs, but your organization deals only with children's health, refer her to a couple of local senior organizations and get her their numbers and contact information. As soon as reporters can establish that you can get them information quickly and accurately—no matter what the information is—they will continue to call you back.

KEEP REPORTERS IN THE LOOP WITH ANY NEW INFORMATION

Make a point of keeping reporters in the loop with what is going on. This may mean that you call them to give them a heads-up on upcoming events your organization is planning, send them any new information you may have, or call them with story ideas. Make sure to keep conversations short but informative. If you make a point of calling them regularly with updates, they will not think that every call you make

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Sample Non-Pitch call to a reporter

Hi Pam, this is Pat Smith from Health Care Today, I am calling to let you know that in February we are going to be releasing some new data that show a change in the number of uninsured. I will keep you updated on when and where we will be holding the press event.

Keep the conversation brief, giving them just enough information to keep them hooked and interested in your event.

UNDERSTANDING REPORTERS

DON'T BE INTIMIDATED BY REPORTERS

Reporters work on tight deadlines and usually don't have much time to find the information they need. For this reason, many people are intimidated by reporters and think that they come across as rude and pushy. Remember that they are only looking for the right information to plug into their stories and usually have little or no time to find it. Once you understand this dynamic and play an important role in helping them get the information they need, you will be on your way to developing solid relationships.

DON'T CALL REPORTERS ON DEADLINE

The number one rule to keep in mind when talking to reporters is never to call them after 3:00 p.m. unless you are giving them information they need for the article being filed that evening. The last three hours of reporters' days are a frenzied time when they are attempting to get last-minute facts and quotations for their articles. The best time to make a pitch or follow-up call is usually before noon.

DON'T CALL REPORTERS WITHOUT A REASON OR EXCUSE

The number two rule to keep in mind when talking to reporters is not to waste their time. Make sure you have a reason to call. The reason can be to make an introduction, to provide information, to give them a heads-up on an upcoming event, etc. Reporters do not have a lot of time, and for this reason it is important to establish yourself as a useful contact.

DON'T CONFUSE A WORKING RELATIONSHIP WITH A FRIENDSHIP

As you develop relationships with reporters, don't tell them anything that you wouldn't want them to print in their newspapers. Never forget that their number one goal, no matter how much they might like you on a personal level, is to get a good story. Don't let a warm relationship with a reporter lead you to say things about Administration officials, colleagues, legislators, or candidates you don't want seen in print. Reporters take their jobs seriously, and they will print anything you say that seems newsworthy.

DO ESTABLISH YOURSELF AS A HELPFUL RESOURCE

When reporters call you for information, be as helpful as possible—even if you cannot answer their questions directly. If their request is not applicable to your organization, refer them to other Web sites, telephone numbers, or organizations. If you establish your organization as a one-stop shop where reporters can get background information, referrals, and an interview from your spokesperson, they will keep calling you back.

CONCLUSION

Successful relationships with reporters are relationships in which the organization is able to get its message out through the media because it supplies accurate and timely information to reporters. Reporters need information in order to write good stories. Therefore, once you position yourself as a resource and always help them get the correct information, you can even get your message into health care stories without a press event.

Sample Media Call Sheet

Media Call Sheet

Name: Matthew Collins, Health Beat Writer

Media Outlet: The Daily Herald (Print)

Contact Number: (657) 222-2222 ext. 158

E-mail: matthew.collins@dh.com

Fax: (657) 222-2221

Date: Monday, Feb. 25th

Requests: Comment from organization and information on its local effects.

Story Topic: High cost of RX

Deadline: 1:00 p.m. Today!

Action Taken: Jane spoke with him. We also sent along our new report.

Call Received By: PSS

ImPRESSive

A MEDIA TIP SHEET FOR ADVOCATES

Families USA ı December 1998

Creating Working Media Lists

THE IMPORTANCE OF MEDIA LISTS

A media list is a basic, yet essential, tool in media work. Use it to pitch stories to media; invite them to events; mail reports; and send press releases. Since the media list is something you will need each time you reach out to media, the information you include must be useful and accurate.

GETTING STARTED

There are many sources to aid you as you prepare media lists. Reading the newspaper, watching television and talking with other professionals who work on the issues you care about are good ways to find out who should be included on your media lists. Also, many news outlets have websites that give you access to their publications and staff, and some allow you to e-mail reporters directly.

There are directories that provide contact information for media outlets and contacts, but they are often expensive. Consider borrowing a list from a coalition member or using your local library.

The best way to build an accurate media list is by phoning individual media outlets. You don't necessarily need to speak with each reporter. If the outlet has a switchboard operator, let him or her know that you are updating or preparing a media list and would like information regarding some specific contacts. Interns can be useful in doing this work, but be sure they understand the need for accuracy.

Sample Script:
[to switchboard operator/receptionist]

Hi. My name is Nancy Julian with Hawaii for Health, and I'm in the process of updating my media list. Will you please tell me the name, title, phone number and fax number of the person who covers health care issues at your outlet?... Thank you for your time.

Note: *Be sure to ask for the correct spellings of first and last names.*

DECIDING WHAT LISTS TO CREATE

There are several factors to take into account when deciding what types of lists you need to create. You should have a general healthcare list made up of a variety of contact types (reporters/editors/writers/producers) that cover healthcare issues. This list will probably be the one you use most often. In determining what additional lists you need to create, assess which types of outlets and contacts are appropriate for the kind of work your organization or coalition does. Consider the following divisions:

By Outlet Type: Radio, Television, Print, News Services
By Contact Type: Healthcare Reporters, Editors/Assignment Editors
By Coverage Area: Local outlets, Regional outlets, National outlets

DECIDING WHICH MEDIA OUTLETS TO INCLUDE

Your list should include both print and broadcast media. Print media is comprised of newspapers (both daily and weekly) and periodicals (newsletters and magazines). Broadcast media includes radio and television.

While you should target the major outlets in your area, also pay attention to smaller outlets, such as ethnic publications and college radio stations. Be sure to include radio and TV talk shows as well. The more outlets you target, the better your chance for coverage, so think broadly in terms of the available media.

EXPLANATION OF BASIC MEDIA JOB TITLES

Assignment Editor- If you do not have a specific contact at a print or television outlet, calling the assignment desk to speak with an assignment editor is a good place to start. An assignment editor or managing editor tracks news leads and decides which department will follow up.

Beat Reporter- A reporter's beat is the particular issue or topic that she or he covers. Local newspapers often have few staff members, so their reporters cover a broader range of issues and usually have more general titles (i.e., staff reporter, writer). The opposite is true of regional or national papers, which often assign reporters to specific beats such as "Health Reporter," "Welfare Writer," or "Capitol Correspondent."

Radio outlets usually do not have reporters who cover specific issues, so you would target the news assignment editor when pitching a story to a radio outlet. Television stations may have consumer or health reporters. If not, the assignment desk is the place to start when pitching a story.

Keeping these factors in mind, look for reporters whose titles best suggest they would be interested in your issue. In instances where a reporter's title does not clearly indicate the topic she or he covers, call the reporter or switchboard operator and ask if that reporter is the appropriate contact. If not, the operator or reporter should be able to point you in the right direction.

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Editor- An editor within a particular department decides what stories his or her department will cover. The departments vary from outlet to outlet. Some examples of departments are Business, Health and Features.

Editorial Board Members-The editorial board ("ed-board") consists of a newspaper's editorial writers. They hold meetings with leaders of the community, advocates, and others who might have an issue that needs to be brought to the public's attention. They then determine if they will editorialize that issue. Some outlets hold these meetings regularly, while others conduct them as needed.

Op-Ed Page Editors-Whereas editorials are written by a member of the paper's editorial department, an op-ed is an opinion piece written and submitted by a member of the community. An opinion page or "op-ed" editor decides which op-eds will be featured on the opinion page. (Look for upcoming issues of ImPRESSive for more on placing op-eds and editorials.)

Producer-In radio and television, the producer is responsible for organizing all the elements that bring a story or program together. The producer decides which segments will comprise a news story, including who will be interviewed. For talk shows, producers determine guests and subject matter.

OTHER CONTACTS

News Services (i.e., Associated Press [AP], Knight-Ridder, Reuters, United Press International [UPI])-A news or "wire" service is a news outlet that tracks stories which are then wired by computer throughout a city, region, state or country. News services are a great way of maximizing the number of outlets that place your story. Since most other outlets get information from news services, if an outlet doesn't cover a story directly they may use the wire version. When pitching a story to a news service, start with the assignment editor or ask the switchboard for the appropriate contact for the issue you're addressing.

Daybook-The daybook, which is a calendar of news events, is distributed to reporters daily through a news service. Daybook editors should receive your media advisory, which contains the who, what, when and where of your press event.

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ORGANIZING YOUR LISTS

Once you've decided who should be on your list, there are several pieces of information to include:

- Name (be sure to spell names correctly)
- Title
- Outlet
- Beat
- Mailing address
- Phone number
- Fax number
- E-Mail address
- Outlet type (print/radio/tv)

The best media lists go beyond general contact information and contain more specific information about your experiences with individual reporters, so it's important to supplement basic information with your own notes. If space allows, include the following.

- Summary of phone or written communications;
- Names of the reports you've sent to the contact;
- A history of stories the contact has covered pertaining to your interest;
- The contact's preferred method of receiving press releases; and
- Information about their approach or biases (i.e., needs a lot of data; prefers stories of "real people"; a friend of managed care).

USING YOUR LISTS

Usually, you will not need to use your general healthcare list in its entirety. Depending upon the nature of the event you are holding or the information you are releasing, you may only need a subset of that list. For each event or release, target the type of outlet that is most amenable to your story. Most stories are suitable for print and radio. If your story is visual in nature (e.g., you will be holding a press conference about Medicare in front of a nursing home), target television as well.

WHO SHOULD BE ON YOUR MAIN MEDIA LIST

Newspapers

News:

- Assignment Editor
- Editor
- *Beat Reporter*

Community Events:

- *Calendar Section*

Editorial Page/Opinion Page:

- *Editorial Page Editors*
- *Editorial Board Members*
- *Op-Ed Page Editors*

Television

News:

- *Assignment Editor*
- *Features Editor*
- *Beat Reporter*

Talk Shows:

- *Producer*

Radio

News:

- *News Director*

Talk Shows:

- *Producer/Booker/Host*

Magazines/Community Newsletters

- *Editors*
- *Reporters*

News Services

- *Assignment Editor*
- *Daybook Editor*
- *Beat Reporter*

Weeklies

- *Editor*
- *Calendar Section*

While it is important to develop rapport with reporters and editors, be careful not to overuse your media lists. Call or send materials to reporters or editors only for those specific issues and events that you know will appeal to them.

UPDATING YOUR LISTS

It is extremely important to update your lists on a regular basis to ensure that the information you disseminate reaches the intended contacts. Media outlets often have high turnover rates, so the health reporter you contacted for your last release may no longer be employed at that outlet or work the same beat. Call each contact or outlet before a major release or event to ensure you are reaching the appropriate person.

Once the release has gone out, you will probably learn of more changes when you pitch the story, as you are referred to alternate contacts, so be sure to update your lists after your event.

CREATING A DATABASE

A database allows you to select particular contacts from your larger media list and is a tool for using your records with ease. It should be more flexible and sophisticated than a word processing program. An efficient database will:

- Allow you to quickly search for individual contacts within your lists;
- Include a sorting function that allows you to create subsets of your lists for projects that don't require use of the full list (e.g., just radio outlets, just consumer reporters);
- Alert you when you are entering a contact that is already in the database to avoid multiple listings of the same contact;
- Allow easy updating of records;
- Provide room for additional comments you wish to include;
- Allow you to merge letters; and
- Organize your information in a user friendly, accessible format.

Basic programs such as Microsoft Access will work fine for your database. Since such programs may already be installed on your computer, you will save money by avoiding the cost of purchasing specialized database programs.

ImPRESSive

A MEDIA TIP SHEET FOR ADVOCATES
Families USA | July 2002

On the Record & Off the Record: Controlling the Story

Are you intimidated by talking to reporters because you don't know WHAT they will write? Knowing and establishing the parameters of a discussion or interview before giving reporters information will allow you to control the message and help shape the story.

There are four kinds of verbal agreements you can establish with a reporter. Before you answer any questions, it is always a good idea to determine how your answers will be used. You can do this by establishing whether you are speaking to a reporter "on the record," "not for attribution," "off the record," or "on background." Each level of conversation determines how much of what you say can be used in the story. You can deliver your organization's message effectively through each of these methods, and more importantly, you can use each of these methods to shape the story.

ON THE RECORD

Speaking on the record is the most direct means of delivering your message. When talking to a reporter on the record, it is understood that anything you say can end up in the story and will be attributed to you. Once you establish that you are speaking on the record, you cannot retract anything you have said. Therefore, talking on the record is the equivalent of talking into a microphone or into a tape recorder. On the record should be used when you want to get your organization's message out to the media through your spokesperson.

When speaking on the record, it is extremely important to stay on message and to not stray from your talking points. You will not be given the opportunity to retract a statement or to take back anything you said. Therefore, you should make sure to say only the things you want to appear in the story. Stay on message.

To prepare for an on-the-record interview, you should decide what message you are trying to communicate. Talking points are good tools to prepare before your interview. In addition, you can practice your talking points and discuss your message with someone else. In preparing for the interview, try to anticipate what questions are going to be asked and plan how you will answer these questions in a way that gets your message across effectively. An on-the-record interview works best when it is controlled. An on-the-record interview should never be conducted spontaneously.

Tips for Speaking on the Record

- **Never speak on the record without knowing everything about the interview:** You should never talk to a reporter on the record if the reporter calls you out of the blue and doesn't specify exactly what the piece will focus on. If this happens, you should take a message and then call the reporter back. This way, you can figure out what the reporter is writing about and anticipate the questions that might come up. Calling the reporter back once you are prepared puts the ball in your court so that you have better control over what is said during the interview.

- **Don't let the reporter take you off message:** Continue to bring them back to your message. Don't worry about sounding repetitive. The more you repeat your talking points, the more likely it is that your points will get across. Your goal when speaking on the record is to get your message out through direct and clear talking points even if this means that you are repeating them over and over again. Reporters can only *use* what you give them, so only give them what you want them to use.

- **Answer only the questions you feel comfortable answering:** If you are asked a question that you did not expect, but you know the answer and it is something you feel comfortable answering on the record, then you should briefly answer the question. If the question takes you off message, answer it briefly and then link it to your original talking points.

- **Don't fall for the silent trick:** Reporters often use silence as a technique to get their interviewee to continue to talk and add a comment that is not scripted. Don't fall for the silence. Answer the questions using your talking points and then wait for the next question. If you begin to feel uncomfortable and start to talk, you will very likely say something that you did not mean to say.

- **Pass on questions if you do not know the answer:** Even the most seasoned interviewee sometimes gets unexpected questions. If you do not feel comfortable answering the question or, worse yet, you do not know the answer, you should feel free to pass. For example, if your interviewer asks you about a particular piece of legislation that you are not familiar with, you can answer in the following way:

  - "I don't know the answer to that question. I'll have to get back to you with that information,"

  - "I don't know that off the top of my head. Let me get back to you later," or

  - "That is not really within my area of expertise, but I would be happy to get that information to you later."

Remember, it's better to admit you don't know the answer than to have an inaccurate quote in the paper.

- **Juggling between staying on message and not stonewalling the reporter**: There is a big difference between continuing to bring the interview back to your message and not answering a question. You don't want to sound like a broken record, but you also want to control what is being said in the interview. Therefore, you should prepare talking points that say your points in many different ways, and you should anticipate how you can answer a variety of questions with your talking points. Answer the questions and quickly tie them back to your message.
- **Don't be a fickle source:** Once you have established that you are speaking on the record, it is not advisable to change your mind mid-sentence and to attempt to retract your statement. If you do, you run the risk of the reporter printing it anyway. More importantly, you will damage the relationship you have with the reporter. If you ask a reporter to not use something you have already said, you are breaking your agreement. This will ultimately harm your relationship with that reporter. They'll no longer come to you as a reliable source.

Sample Script for Keeping an On-The Record Interview On Message

Imagine that the focus of your interview is the importance of a real prescription drug benefit in the Medicare program.

If the reporter begins to ask you about patent abuse and different drug litigation cases, you should answer the question briefly and then return to your original message, which is that all of these lawsuits exemplify the need for a real and meaningful prescription drug benefit within the Medicare program.

NOT FOR ATTRIBUTION

Not for attribution is an agreement in which a reporter can quote what you say but cannot attribute it to you. Therefore, the article would use your quote but attribute it to a health care advocate. Quotes that are not for attribution appear in the paper all the time. Articles that say things like "a senior White House staffer said" or "a source close to the campaign said" are all based on information that was revealed because the reporter agreed to not attribute it to the source.

Not for attribution can be used to leak information that you would like to see in print but that you would not want your name associated with. The quote has validity because it does attribute the information to someone who would be in the know, but it is not as direct as an "on the record" quote. Not for attribution is usually reserved for juicy bits of information that you know a reporter is going to be itching to print when you do not want your name or organization associated with the quote.

Negotiating a not-for-attribution agreement can be tricky, and it must hinge on two very important elements. 1) You must make this verbal agreement BEFORE you give the reporter any information. The reporter will probably try to get the information before giving up the right to attribute it to you. Don't let her. As soon as you give up the information, you lose the right to control the source of the quote. 2)You should only work with reporters that you trust when giving up information that you do not want attributed to you. Not for attribution relies heavily on trust. Therefore, if you do not already have a working relationship with a reporter, you really have no basis of knowing if he or she will break your agreement.

Script for Establishing a Not-for-Attribution Agreement

You:	I have some information that you're going to find interesting, but you cannot quote me on this. (If you feel that you need to have further clarification.) My name cannot appear anywhere near this information.
Reporter:	What is it? Is it good?
You:	It's very interesting, but I am not giving it to you until you agree not to attribute this to me.
Reporter:	Is this necessary?
You:	Yes.
Reporter:	Okay, I'll say it's from a health care advocate.
You:	Alright, here's the information....

OFF THE RECORD

The main difference between off the record and not for attribution is that information you give off the record cannot be printed in the story. If you establish that a conversation is off the record, the reporter MUST find a different source to give her that information before she can print it in the story. If the reporter prints something you said off the record, that reporter has broken your agreement.

Types of information you would give a reporter off the record:

- Information that you feel would help the reporter better shape their story but that you do not want to see in print.
- Information that you have heard, but you can't verify if it is true and therefore you do not want to be the one that leaked the information.

In order to establish an off-the-record conversation, make sure you do not give any information to the reporter until you have received a verbal agreement that it cannot be printed in the paper. The way it works is that a reporter comes to you with a question. You must then establish that you will answer if the reporter agrees that it is off the record. For obvious reasons, most reporters will try to talk the information

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out of you before making this agreement. Therefore, it is extremely important that you remain firm and do not reveal any information until you come to a verbal agreement that the reporter will not use any of the information you are sharing. If the reporter cannot give you the verbal acknowledgement, then you should move on to the next question.

On Background

When speaking to a reporter on background, you are giving the reporter important information they will need to write the article. This is usually when you give reporters data, a historical context for their story, and other information that shows relevance and helps shape their story.

As with not for attribution and off the record it's important to establish that the information exchanged is on background before you give the reporter any information. Simply saying "I can talk to you only on background" can do this. If you give the reporter the information before you establish that it can only be used on background, you run the risk of having data as your quote in the article instead of a tight quote that better conveys your message.

It's important to remember that just because you are not being quoted directly does not mean you should not stay on message. On background can be an effective means of delivering your message, as long as you remain focused and give clear data that back up your talking points. Therefore, instead of spouting figures and numbers, take some time to figure out how the information you have will best support your talking points and message. This is not the time to tell both sides of the story or to give the reporter any data that supports your opponent's points. Leave the objectivity to the reporter—that's her job. You should just focus on getting your points across clearly and effectively.

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Script for Establishing an Off-the-Record Conversation

Scenario:

You are talking to a reporter about a piece of legislation. You have heard that a certain state senator has decided to support this piece of legislation. Nevertheless, you do not have any proof that this is the case. This state senator is someone your organization never works with and who historically never supports your issues. You find out through your conversation with the reporter that she is not thinking that this piece of legislation stands a chance of getting anywhere. Therefore, you feel that if she knows that this certain state senator has decided to support the bill, she would change her mind. Nevertheless, you know that if the information gets printed, you run the risk of losing this state senator's vote.

Striking the Deal:

Reporter: This bill goes before the state senate every year and every year, it fails to pass. What makes you think that this year is going to be any different?

You: I have heard something but I cannot tell it to you on the record. If I tell you, it has to be off the record.

Reporter: Is this necessary. What did you hear that I couldn't possibly tell my readers?

You: This must be off the record or I can't answer your question.

Reporter: Okay, I agree that we are speaking off the record. What is it?

You: I have heard from a source that state senator x has decided to support this piece of legislation.

- OR -

Reporter: You agreed to speak on the record. I don't want any information if I can't quote you.

CONCLUSION

The most important aspect of speaking to reporters is to be candid and up-front about how you would like to have your information used in their story. Remember, you lose all bargaining power as soon as you have given up your information. Therefore, make sure to be open and clear about how you would like them to use the information. A reporter cannot be mad if you give them information off the record after they have agreed to listen to it off the record, but if you decide that something you already said should have really been off the record, you run the risk of having the reporter print the information anyway or, even worse, of severing ties with you. Don't be intimidated about standing your ground and controlling how you would like your information to be used. By navigating these four ways of communicating with reporters, you will be able to successfully control how reporters shape their stories and get your message out through the media.

ImPRESSive

A MEDIA TIP SHEET FOR ADVOCATES
Families USA | April 2000

How to shift focus on a story

Some people think that the only bad media coverage is no coverage at all. In some situations, and for some people, this is true. More than likely, however, you need the media and the public on your side. The only people who can really afford bad press are characters like Howard Stern, not grassroots campaigns such as yours. In order to get the support of the public, you have to make sure that your message is conveyed by the media. But what do you do when you are working on an issue that needs a lot of public support and the media portrays your viewpoint unfavorably? Here are some tools for not only dealing with negative media coverage, but also improving your media coverage over time.

FREE VERSUS PAID MEDIA

The ability to shift focus on a story is very important to any type of campaign since you cannot control the kind of coverage your issues receive. As advocates, your most powerful tool is "free" media. This is media time you do not have to pay for; for example, newspaper articles or radio interviews that mention your organization. Paid media is, clearly, media time you must buy. Television commercials and newspaper advertisements are two examples of "paid" media. Your goal as advocates is to make the most out of the free media time available to you.

A STORY BREAKS

Imagine that the major newspaper in the state runs a story about the implications of expanding coverage to non-parental adults. Your organization is advocating such an expansion. Before the story ran, the reporter contacted you for comments but your quotes are buried at the end of the article. Instead, the story focuses on the financial costs of an expansion and has legislators insisting that the expansion would be feasible only if higher taxes could be collected. This is not the position your organization needs to be in to convince the public and legislators that the expansion is necessary.

WHAT DO YOU DO?

No matter how you react, you have to move quickly to determine what your course of action will be. The longer you let the opposition dominate the press, the more likely the story will stick in the public's mind. The opposition has already scored the opening shot, so it's important that your return be quick, convincing, and on-message.

Before you do anything, figure out where the story broke and what kind of "legs" it had (how long it lasted). Having this information puts you in a better position to make decisions about how to respond. For example, say the story broke on a Saturday in the back pages of the metro section, after pages of advertisements. The likelihood of this story seriously affecting your program is small since fewer people read the newspaper on Saturdays. Be very careful in gauging your response. You don't want to call attention to a story that was overlooked.

On the other hand, say the story gets picked up Monday morning by the popular all-news radio show that everyone listens to on the way to work. This is much more likely to cause a problem. You may not have a problem just because a story is printed, but a story that generates a lot of interest and gets picked up by other newspapers or radio and television could be a more serious matter.

Think Before You Speak

In our scenario, the non-parental expansion story appeared in the front pages of the major state newspaper this morning. You know you have to respond, but you're not sure what to do. Your first instinct may be to call up the reporter and give him or her an earful. This is definitely a mistake. Don't vilify or alienate the reporter who wrote the article. It could be that he or she did not understand your viewpoint or maybe his or her editor was looking for a certain kind of story. Look to the future: This reporter could be the only person who covers health care for a newspaper in your city.

You should call the reporter, but don't be antagonistic. Instead, present your side of the issue and add any new information. While it is unlikely that he or she will write another story (and even less likely that he or she will receive permission to do so), it's worthwhile to keep a relationship with the reporter. Perhaps future articles will be more sympathetic to your side. You don't have to be best friends with the reporter. What you do want is to be the first person or group that this reporter thinks of when he or she sits down to write a story on your issue. In order to maintain a good relationship, you should **promptly** return phone calls and help the reporter gather information he or she might need.

Now, let's say that the story has broken big and has been picked up by other newspapers and several important radio stations. You need to generate public support and media attention. You have quite a few options open to you. You don't necessarily have to use every tool at your disposal, but here are some tried and true strategies to shift focus.

Spin

The most important thing to remember is that everything you say and everything you do has to portray your issue in the most favorable light. This is basically what spin is. In order to do this effectively, you have to know what words and aspects of your issue resonate with the media, legislators, and the public. Listen carefully when your issue is attacked. Pay attention to what words are used to portray your issue in a negative light and then use that information to your advantage.

For example, if the opposition characterizes your proposal to provide health care for non-parental adults as increasing costs for other working adults, show how insured adults actually pay more because others are uninsured. If cost is your weakness, downplay it and find other ways to show that the proposal would benefit the community.

Focus on convincing the media that the people who would benefit from the expansion are real people struggling to make ends meet. Be careful to use language that reinforces the positive aspects of the expansion.

It is a good idea to sit down and draft some talking points for you and your supporters. Talking points clearly define your message. They are short, sound-bite sized phrases that contain the main points of your message. They are easy to write and save organizations lots of time. The idea is that you write down the three most important things that you want to be known about your issue.

For example, in the non-parental expansion, the three main points might be:

- over 12,000 working people in the district would benefit from the expansion
- the people who would benefit are low-income working people whose minimum wage jobs do not provide coverage and whose income makes private insurance cost-prohibitive
- in a recent poll, over 75 percent of voters believe that this expansion is necessary

These are the main points that you want to be everywhere: in newspapers, on the radio, on the tongues of legislators. The only way to get this message out is to be disciplined about it and stick to the points.

Editorial Boards

No matter where the story broke, try to organize a meeting with the editorial board of the local newspaper. This is very easy to do. Call the editor of the newspaper and tell him or her that you would like to sit down with the editorial board to discuss your issue. Set up a date and time and start working on your presentation. The presentation should be concise, persuasive, and on-message at all times. The ease with which you get a meeting with the editorial board belies the importance—and the opportunity—such a meeting presents your organization.

The editorial board includes editors and some staff members who approve the editorials the newspaper prints. These are the people who decide the perspective of the editorial and assign someone to write it. Your objective in meeting with the editorial board is to persuade them—with statistics, facts, and your strongest arguments—to take a more favorable opinion toward your position. You may see results quickly, such as an editorial favoring your proposal; or you may see a general change over time with better or more sympathetic reporters covering your events.

Op-Ed Piece/Guest Columns

Guest columns and op-eds are two great ways to get exposure for your point of view. An op-ed appears on the page opposite the editorials, hence its name. Guest columns also appear on the op-ed page but are distinguished from op-eds by a few minor differences. Op-eds are usually written about an issue that has recently been reported in the newspaper. It's a great idea for a few groups to sign and submit one op-ed. Guest columns are written by one person. They can be about anything and are not limited to issues the newspaper has recently covered. What sells newspapers on guest columns is the notoriety of the author and the quality of the writing.

Generally, these pieces are long—about 700 words. Each paper has different criteria, so it is best to call the editorial department before submitting your piece. Make sure to attach a cover letter explaining what you are sending and who you are. In the letter or guest column, provide your best, most persuasive arguments for the proposal. Be as clear and jargon-free as possible. Remember that newspapers are written for a 5th or 6th grade reading level, so you need to write simply to reach the maximum audience.

Letters to the Editor

Letters to the editor give citizens a forum for commenting on newspaper articles. Anyone may write them but there can be some limits on how many one person may write in a year. While it may seem to you that the more letters written, the better coverage you will receive, you have to be careful. These letters must always be authentic, meaning that if an editor receives 400 identical letters, he or she will not print them. This doesn't mean that you should limit your supporters. It is advisable that each person write his or her own letter, possibly drawing from some talking points that you may draft for them. References to a recent article in the paper make your letter more likely to be printed.

Letters to the editor are generally short, about 250 to 300 words, and can be written from an organization or a citizen. You must identify yourself and provide necessary contact information. Without this information your letter will not be published. Newspapers usually print their requirements on the editorial page, so you can easily find out who to send your letter to and what information you will need to provide. (For more hints on op-eds and letters to the editor, check out the March 1999 *ImPRESSive*.)

Humanize the Issue

No matter what you do, you must remember to humanize your position as much as possible. This could be your strongest asset. The media will be interested in interviewing people who would benefit from your proposal. They will want to see what will happen to these same people if the proposal does not pass. Try to collect stories of people who would benefit from the program and let reporters know that these people are willing to be interviewed.

It's great to have lots of people volunteer to speak to the media, but you have to carefully choose who will actually be interviewed. The person you choose will be representing the program to thousands of people. He or she will be the human face that is associated with your efforts to expand coverage. It is important that he or she be sympathetic. Be sure to verify all the information this person gives you if you do not know him or her personally. Take time to speak with him or her before you allow any interviews. You might want to ask possible interview questions and practice responses. It's better to spend more time beforehand and prevent a mistake than to try to clean up after one. (The July 1999 *ImPRESSive* explains how to set up a storybank and how to collect useful stories.)

Press Event

If you want to stage a press event to offset negative coverage, the most important thing to remember is to make it newsworthy. All the time and effort you put into organizing will be futile if you can't generate some media interest; after all, that's what you're after.

A few days before the event, send out a media advisory. This will inform reporters of who will be participating, when, where, and what the event is all about. You should make follow-up calls right before the event, making sure that they received the media advisory, asking if they have any questions, and reminding them about the press event. The day of the event, send out a press release (embargoed until the time of the press event) and have releases to hand out at the event.

As for the substance of the event, if at all possible, try to refute the opposition's claims with hard facts. Take the example of the expansion. Find academics willing to speak about the feasibility of the expansion. Prove that increasing coverage to adults would actually save money, especially out of the taxpayer's pocket. Provide statistics to refute the opposition's claims. Have doctors and nurses speak about how important it is that all adults have insurance and what that would mean in decreased visits to emergency rooms. Be sure to have someone present who would benefit from the program. It's easy to deny numbers on paper; it's harder to confront a real person without health coverage.

Invigorate Advocates
Do what you can to shift focus on the story, but remember that negative press can be a powerful tool in motivating advocates to work together. There's nothing like anger to get people working for a common cause. Use the media attention to pull together different groups who might not ordinarily work together but who have a vested interest in getting the proposal approved. For example, after a negative story appears, approach doctors' and nurses' organizations, labor unions, religious and cultural groups, as well as your traditional partners, to form a coalition.

HOW TO GET THE MOST OUT OF "FREE" MEDIA

Free media is an advocate's best friend. With your limited budgets, you can't afford to run frequent ads in newspapers or buy television air time to publicize your issues. What you can do is employ free media, so named because it costs nothing but the effort you put into it. Here are some examples of free media:

Press Advisory
This is written on your organization's letterhead and advises reporters of an upcoming event.

Press Release
This is also written on your organization's letterhead and informs reporters of the release of new information.

Press Statement
Also on letterhead, a press statement gives your organization an opportunity to respond to something; an event, a speech, a report, etc. It should be attributed to the director of the organization or someone equally well known. All it contains are quotes from the director. This gives reporters covering the event, speech, report, etc. an opportunity to quote you.

Note: You should use press statements, releases, and advisories judiciously because reporters hate to receive a lot of unsolicited material.

Web Site
There are places on the web that will help you set up a free website. One such site is {www.homestead.com}. Web sites are really useful because you can direct reporters, legislators, and other advocates to your site for current information. You can also set up a guest book where people can write comments about the issue. It's a great way to share information, target possible partners, and locate real people with similar problems.

Developing a Rapport with Reporters

You know why. Here's how:

1. Return phone calls promptly.
2. Provide information, if you can.
3. Direct them to other resources.
4. Respect deadlines.

CONCLUSION

The ability to shift focus on a story is an important tool for advocates. As in a debate, you have to be quick, clear, concise, and you have to use your opponent's arguments against him or her. This takes discipline to accomplish, but employing these tools will strengthen the reporting your organization and issues receive.

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ImPRESSive

A MEDIA TIP SHEET FOR ADVOCATES
Families USA | October 2000

Tips for Interviews
Part I: Newspaper

Giving an interview for the first time can be daunting, to say the least. You are probably nervous about getting all your information right. Maybe you're concerned about sounding like a fool in your quotes.Or it could be that the idea that your words will linger forever in the newspaper's archives strikes fear into your heart.

Despite these misgivings, you are willing to be interviewed because you know that it will further your cause. You realize newspapers are a valuable tool in educating the public and swaying decision-makers and for these reasons, you feel it's important to give interviews. The question is how to prepare for them.

Let's say Jane Smith from the Generic County Reporter is doing a story on the Children's Health Insurance Program (CHIP). In the past, you've helped her gather information and you think that she's a credible reporter. Today, you received a phone call from Jane. She's interested in setting up an interview for an article she's writing on your state's ability to enroll kids in CHIP. You've never been interviewed before, and you're not sure what you should expect. Here are some tips for making the interview as successful and painless as possible.

SET CLEAR GOALS FOR YOURSELF

You should never agree to an interview unless you are sure of what you want to convey. Not all press is good press. If you sound like you are uninformed or your message shifts erratically in the interview, you will not help your cause. Before you begin, consider how this article could be helpful to you and your ultimate goal of enrolling more children. Then, think about whom you want to sway and what language or arguments would best accomplish that.

Use your goals to determine your "message." Your message could be something concise like "Kid Care Now" or "Don't Play with Kid Care." Throughout the interview, you want a clear theme to develop. That's your "message."

BE PREPARED

Before the interview, you should prepare possible questions you expect the interviewer to ask and come up with answers to those questions. Then make an effort to sit down, preferably with someone else to help you, and practice your responses. Try to be clear, concise, and interesting. You don't want to drone on long after the reporter has stopped taking notes. Remember, you should have a clear message you reiterate when appropriate. For example, in preparing for your interview, you and another organizer have come up with some possible questions a reporter might ask:

- How many children have been enrolled in the CHIP program since its inception?
- How many children are eligible but un-enrolled in the program?
- What are some barriers to their enrollment?
- What measures has the state taken to remove these barriers?
- If no measures have been taken as of yet, what are your recommendations for removing those barriers?

When brainstorming your responses, try to find ways to insert your message. You don't need to use your catch phrase in every response, but the general message should be conveyed as often as possible.
When practicing, try to anticipate difficult questions the reporter might ask you. Find different ways of answering the question and consider possible follow-up questions. When brainstorming responses to tricky questions, think two or three questions ahead to see where the reporter might try to lead you. It sounds like a lot of speculation, but it's worth it when a little forethought can help you avoid a sticky situation.

In the interview, you want to respond to the reporter, not just answer her questions. That means you want to tailor your remarks in such a way as to lead the reporter back to your key point, your "message." If you feel that the interviewer's questions are straying away from the real issue, steer the dialogue back to the topic by saying something like, "That's an interesting question, but I think the real issue is . . ." or "While that may be one aspect of the problem, the greater issue is . . . ." You don't want to antagonize or appear to belittle the reporter, but you also don't want to jeopardize the value of the interview.

The reporter has been trained to think of the interview and the story as hers. Therefore, you shouldn't expect her to docilely follow what you think the agenda for the interview should be. There's a certain tension between any good reporter and her savvy interviewee. It's your job to get your points across as effectively as possible and still maintain a mutually beneficial relationship. It's in her interests to fold your perspective of the issue into the story she envisions.

You should realize that most interviews will take place without a lot of preparation time for you. You shouldn't expect to have much advance notice. Therefore, by the time you present yourself as a resource for journalists, you should have already practiced and given considerable thought to your interview techniques. You don't want to be caught off-guard.

Before the interview, consider:

- How will this interview further your goals?
- Whom do you want to sway/impact?
- What is the best language/argument to sway these readers?
- What do you hope to get across in this article?
- What questions do you expect to be asked?
- What information do you want to convey?
- Are you prepared?

UNDERSTAND THE REPORTER'S NEEDS

Some reporters at a newspaper have a specific beat, or topic area, that they are expected to cover and on which they can be very knowledgeable; others are general assignment reporters, or reporters who are expected to write on a variety of issues that may constantly change. When a reporter first approaches you for an interview, you should determine how much she already knows about the subject. Oftentimes, reporters new to the topic will inform you that they will need more than the usual amount of background information. This presents you with an excellent opportunity to educate them and strengthen your professional relationship. Good information from you now will make it more likely the reporter will rely on you in the future. If you are working with a reporter new to CHIP, for example, it's a good idea to give her as much comprehensible background information as you think necessary to understand the issue. This doesn't mean that you should fax her a hundred-page treatise on why the state is doing a rotten job signing up eligible children. What you should do is give her one to two pages of background information and let her know about any informative and easy to use websites that are available. A bulleted fact sheet would be easy to read and quickly convey the key points. Remember that reporters need to prepare for interviews almost as much as you do. They'll appreciate the extra information and the opportunity to prepare their questions in advance of the interview.

If the reporter is an old hand on the subject, you don't need to steer her toward any information unless you think she is unaware of something new that is integral to the topic. In this case, you might want to mention the new piece of information and let her know where she can find it. If the reporter asks you about any new information, you should feel free to let her know about the latest data available, for example.

THE FORMAT

Most interviews take place over the telephone. The reporter may call you a few hours before her article is due and ask to interview you on the subject. She'll ask you to spell your name slowly and to give her your exact title and the name of your organization. She may also ask you to succinctly describe your organization. You should say something like "Columbia Citizens United is the largest non profit, non-partisan consumer organization in the state that deals with CHIP and other health issues." You should have a standard description of your organization developed before your first interview.

During the interview, if you falter and inadvertently give incorrect information, make sure to correct yourself as soon as possible. Be as accurate, succinct, and clear as possible, even as you put forward your message. With practice, this will become second nature.

ON THE RECORD VS. OFF THE RECORD

Anyone who's ever seen "All the President's Men" has heard about on the record and off the record. *On the record* means that your words can be used in a story and attributed to you. Ninety-nine times out of a hundred, this is how you should be speaking to reporters. It's rare that you would need to go off the record for any reason. *Off the record* is a gray area that is often dependent on different reporters. Before you enter this murky area, make sure that you and the reporter understand each other about how the information will be used. For the most part, off the record means that your information cannot be used in the article and the reporter cannot repeat it to anyone using you as the source. What the reporter can do is to ask other people to confirm what she has learned from you, on the record. She might ask someone else, "I've heard that Senator Jones originally refused to vote for funding for the CHIP program. Is that true?"

For an advocate, you should almost always restrict yourself to things that can be used on the record and attributed to you. If you're giving reporters information that you don't want to be linked to, you should realize that this situation could easily backfire on you. If you really feel that you must give this information, make sure to let the reporter know that this information is off the record BEFORE you say a word.

You should never assume that any information you give is off the record. No matter how much you trust a reporter, make sure she agrees that information is off the record before you begin speaking.

There are other categories for sharing information with reporters. One is called background. Saying something on background means that you don't necessarily want the information to appear in the story, although it can, depending upon your agreement with the reporter. It cannot, however, be attributed to you. Background information is used to help a reporter frame a story or more accurately understand the context of the issue. The reporter might attribute it to "a source in the activist community" but that should not jeopardize your anonymity. While this information can be useful to the reporter, she will probably still try to have someone confirm the information on the record.

Not for attribution is another method of dispensing information. It can be used in the story, but it should be attributed to a "source."

If a reporter uses a tape recorder to record the interview, it should be turned off before you provide any information that is anything but off the record. No matter your relationship with the reporter, mistakes can be made.

Remember, reporters aren't there to protect you from yourself. If you volunteer too much information; forget to say that something is off the record before you say it; misunderstand what the reporter means when she says off the record, on background, or not for attribution, you're going to be the one who's hurt. The clearer you are in the beginning, the less damage control you'll have to do later.

ENDING THE INTERVIEW

Once the interview has come to an end, make sure the reporter has your phone number (if she did not call you first) or other contact information such as e-mail to insure that she can get in touch with you if she has any follow-up questions as she is writing her story. Get her phone number as well, in case you have anything really important to add. If possible, find out when she expects the story to run. Sometimes, even when a reporter has written a story, it does not run due to the newspaper's space constraints. You never know when a water main might break and drive you from relevance. In closing the interview, make sure to thank her for her time.

COLLECTING CLIPS

If this is the first time you have ever seen your name in print, you probably won't need to hear this advice; however, it's important to collect and file your clips. These clips can be used in soliciting other articles on your issues, can be included in press kits, used in testimony, brought to editorial board meetings, sent to funders, and analyzed for future interviews. And besides, they may come in handy for your organization's 25th (or 50th) anniversary celebration!

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ImPRESSive

A MEDIA TIP SHEET FOR ADVOCATES
Families USA ı December 2000

Tips for Interviews
Part II: Radio

Hearing yourself on the radio for the first time is an overwhelming experience. Part of you is cringing to hear your voice replayed over the airwaves as you discover, to your horror, how many times you say, "um" when you are nervous. You know how important it is to give a good radio interview. Now you need to prepare.

Many of the same skills employed in newspaper interviews are also needed for news and talk radio interviews. You must have a clear goal of what you want to convey in your interview and you must be prepared and knowledgeable about the subject. However, there are some techniques unique to radio that will enable you to give a better interview and will increase your chances of being a resource for the reporter in the future.

Imagine you have recently released a report studying the number of children in your state without access to dental care. You have been approached by several radio producers who want to interview you on this subject. Here's how you can prepare and give a great interview.

FORMAT

In radio interviews, you not only need to be knowledgeable about your subject, you also have to be savvy about the format itself. Try to find out as much as possible about any media outlet that approaches you for an interview. "Outlet" is another name for a news organization or media group. Research the station, program, and interviewer. Using the Internet or a media directory such as *Burrelle's* or *Bacon's*, you should be able to find out who their target audience is, if the program focuses on news, business, or current affairs, and whether or not it has a political slant.

It's important to have this information because it will help you prepare for the kinds of questions you might be asked. Knowing that you will be interviewed on the most conservative talk show in the state will not only help you decide whether or not you want to do the interview, it can also help you tweak your message and anticipate the hard questions.

The first thing you need to find out is what the format for the interview will be. There are talk radio shows that will let you speak almost without constraint for thirty minutes or an hour. Then there are news shows that will give you five to ten seconds to make your case. Although the preparation for both is largely the same, the short news clip, requires much more discipline.

Sometimes talk radio shows invite other guests to speak during the program. If you will not be the only guest, find out how the producer is arranging the show. Will you be speaking at the same time as the other guest, in a debate format, or will you be alone for part or all of the interview? Some producers will book one speaker for the first thirty minutes of the show and an opposing voice for the second thirty minutes.

You also need to know if you will be taking call-in questions. You can find out by asking the producer who booked you or by looking in one of the media books. Learning about the demographics of the radio station will help you brainstorm likely questions.

Think of this as opposition research. You know that the same message will not work with every audience. Therefore, take the time to research the station's audience and particularly, this program's audience. You don't have to radically alter your goals, but you should see the benefit in taking a different tack with very liberal and very conservative audiences.

KNOW YOUR MESSAGE

No matter how long you have to speak, you must stay on message. Otherwise, the interview does you no good and may do you a lot of harm. Before you talk with the reporter, write down what you need to convey as simply and clearly as possible. If you are doing a short news segment, you will have to cut your message to its most basic form; for instance, "Every child deserves a healthy smile." If you are preparing for a longer talk radio show, flesh out your argument with three main points that support your message. For example:

- 3,450 children in Generic County have no access to dental care.
- 235 dentists in Generic County refuse to accept low-income children as patients.
- The School Nurse Association of Generic County says that children with no access to dental care are more likely to miss class and less likely to pay attention in class due to dental pain.

Don't be nervous about repeating yourself over and over. In a taped interview, some of your comments may be cut. Therefore you want to make sure that you convey your message within every response to every question.

Sometimes reporters will try to bait you with a trap questions. Practice deflecting these kinds of questions with phrases like: "While you may have a point, the real issue is . . ." or "I don't believe that is an issue, what is at stake is . . ." If you're in doubt about how to deflect unwanted questions, watch televised press conferences or listen to public radio interviews to see how other people handle them.

PREPARE

Just because you know this topic inside and out doesn't mean you shouldn't prepare for the interview, especially if this is the first time you have been interviewed by this reporter or been a guest on this program. Run through the questions you may be asked with someone who can critique your responses. Feel free to write up notes and use them during the interview, just don't rustle your papers. Try to listen to the program a few times before your interview to get an idea of the kind of questions the interviewer and his or her listeners will ask. Ask someone to run through sample questions with you and get feedback from several people.

(For more information about message development and preparation, see the October 2000 ImPRESSive "Tips for Interviews Part I: Newspapers.")

Before the Interview:

- ✓ Verify time, date, and location or who will be contacting whom.
- ✓ Set aside some time to practice your responses to likely questions.
- ✓ Prepare a press kit to leave with the reporter. Make sure you include your business card.

INTERVIEW CONFIRMATION

Before the interview, make sure you have the directions and the correct day and time of the interview. Sometimes interviews take place at a radio station and sometimes they can be conducted in your office or even over the telephone. Make sure you know who is going where or who is calling whom.

Feel free to ask the reporter how long the interview is scheduled to take and if it will be live or taped. Make sure you know the name of the reporter who will be interviewing you.

PRE-INTERVIEW

Often, the interviewer will request a pre-interview. This may take place a few days or a few minutes before the interview. He or she will take this opportunity to ask you a few questions about the subject. Some pre-interviews are thirty minutes long and some are about 5 seconds! Use the pre-interview to find out what the reporter is looking for from the interview. You can often get a sense of where the reporter would like to take the interview from the pre-interview.

Radio reporters, like print reporters, do not have time to become experts on every subject. They depend on the people they interview to help them better understand the subject. However, do not be lulled into thinking that the reporter will merely ask you soft questions. Reporters are trained to think critically. If there's a chink in your armor, it's their job to find and exploit it.

You Need to Look Good for the Radio: What to Wear

Interestingly enough, it does make a difference what you wear to radio interviews. You don't want to wear jewelry that will create feedback or make noise when you turn or move your head. That means no dangly earrings, necklaces, or bracelets.

DURING THE INTERVIEW

Remember to speak slowly and clearly during the interview, even if the interview is a very short "soundbite." A soundbite is a clip, usually not more than one to two sentences, that reporters insert into their stories to provide a first-hand or expert perspective. You don't want to speak so quickly that no one understands the wonderful message you've worked so hard to craft.

Here's a checklist of things to remember for soundbite interviews. It should also serve as a checklist of important information you should ask producers when scheduling an interview.

If you have a high or squeaky voice, practice speaking slowly and lowly. Likewise, if you are apt to speak in a monotone, try to liven up your speaking style. Ask a trusted friend or colleague to listen and critique your style. You can also record and listen to yourself.

Soundbite Checklist:

- ✓ Who is the interviewer?
- ✓ How long do you have to speak?
- ✓ What is the news peg? Why are you being interviewed now?
- ✓ What is the main topic of the piece?

Try to be as entertaining and active as possible. Give free reign to your action verbs and use your voice as a tool to convey mood. If you're happy about recent legislation that would encourage more dentists to accept low-income children as patients, let that come through in your voice. Use inflection to vary the rhythm of your sentences. For more pointers, listen to your local NPR affiliate. These broadcasters have mastered the art of holding the audience's interest through their voices, no matter the subject.

AFTER THE INTERVIEW

Thank the reporter who interviewed you. Make sure he or she has your business card and one of your press kits, if possible. Ask when the program will air and find out if you can get a copy of the tape for your archives. This is important for many reasons. You can review the cassette to see how you might improve. Pay careful attention to your enunciation and the speed at which you speak. Listen for how well you responded to questions and stayed on message.

CONCLUSION

The ability to speak well and convey your organization's message is an important tool. Being able to give good interviews that further your goals, inform the public, and are interesting and newsworthy to journalists takes a lot of preparation. However, the benefits are clear. With practice and preparation, you'll never say, "um" again.

Sample Booking Sheet

Interview Booked	
Who will be interviewed:	
What day and date:	
What time: (Eastern)	
Interview Length:	
City, State:	
Interviewer:	
Contact person/Producer:	
Who calls? (station or spokesperson):	
Phone number:	
Backup phone number:	
Topic:	
Facts (specific state statistic):	
Station call letters/name of show:	
Format (talk, news, call-in):	
Subject and/or tone of show (friendly, hostile):	
Fax number:	
Date/time show will air:	
Date/time(s) show airs regularly	
Date booked:	
Interviewed by:	

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ImPRESSive

A MEDIA TIP SHEET FOR ADVOCATES
Families USA | January 2001

Tips for Interviews
Part III: Television

Many people consider television interviews to be the "big time"—and with good reason. Studies show that more Americans get their news from television than from any other source. Because of this, many different people and organizations compete for airtime. They know that getting one minute on the evening news can do more to further their issues than almost any other media hit.

Imagine that your organization held a press event about the uninsured in your community a few months ago. You wrote a report with graphs and statistics showing the number of uninsured, their average income, and other demographic information. The press conference was successful, in part because you had real people available to tell their stories and have their picture taken. At the press conference you met Will Clark, a television reporter for KYW-TV. He was very interested in your report and your issues.

Yesterday, the governor proposed a plan to cover the uninsured in your state. Will wants to interview you on-camera for your group's perspective. You've accepted and now you must prepare for the interview.

ANTICIPATE THE REPORTER

Before you ever walk into an interview, your message should have already been established. Message development can take a lot of time and thought so it should be done in advance of any media opportunities. You never know when you'll have the opportunity to talk to a reporter.

When news breaks and you are asked to respond, the first thing you need to do is think of how the news affects your message. How does your organization feel about the governor's proposal? Is it a real solution to the problem of the uninsured or is it merely a political prop for the governor's re-election campaign? These are the kinds of questions you may be asked, so be sure to have clear responses that push your perspective. (For more information about crafting a message, see the October 2000 ImPRESSive, "Tips for Interviews; Part I: Newspaper.")

After you set your message, sit down with a colleague and think through the kinds of questions you'll be asked. Carefully craft short, interesting responses. Remember, this is your opportunity to have your message heard. Repeat your message relentlessly and find ways to include it in your response to every question. Practice responding to tricky questions and ways you can shift the reporter's questions to those more in line with your message.

Once you feel comfortable with your message and your ability to stick to it, begin looking at the way you convey your message. It's important that you look natural on-air so, if possible, try to videotape yourself during these mock interviews. It may seem silly at first, but it will give you the opportunity to critique yourself. If you have done a television interview in the past and have a copy of the tape, make sure to look at that as well. It may give you some ideas about how to improve your posture, gestures, enunciation, and eye contact.

APPEARANCES COUNT

When you are being interviewed, sit up straight and look directly at the interviewer. Resist the urge to look directly into the camera lens. This comes off as overly aggressive and unsettling to the viewer. Try to keep both feet flat on the floor.

Use gestures to make a point. Some people find that holding a pen in an interview helps them with their nerves and gives them something to do with their hands. What you don't want to do is look stiff or artificial.

Speak clearly, enunciating your words. Most of us tend to speak quickly when we're nervous. Try to control the speed at which you speak. Because you've practiced so much, the content of your speech should be second nature. Relax and concentrate on the interviewer. Remember to use your voice as a tool to convey doubt or approval. Using active words to describe the situation will also help keep the viewer's attention.

Smile and be engaging throughout the interview, even when you don't think the camera is on you. The reporter will appreciate this and the audience will pick up on it as well. You don't want to look and sound dour no matter how much you may dislike the governor's proposal. You want to appear active and upbeat.

LIGHTS! CAMERA! ACTION!

1. Sit up straight
2. Avoid large gestures
- 3. Speak clearly and animatedly
- 4. Smile
- 5. Make eye contact with the interviewer

WHAT TO WEAR

Your clothes are very important in a television interview. This is a visual medium and you want to look as polished and professional as possible. In choosing your wardrobe for television interviews, avoid anything distracting or unflattering on camera. You may love that brightly patterned sweater but the camera doesn't. It can distract the viewer from listening to your message. Therefore, try to stick to dark, solid clothing. Avoid white and light-colored clothing. Too much jewelry can also be distracting. Sometimes necklaces rub against lavaliere microphones, obscuring your voice. Large, dangly bracelets can also be distracting, especially if you are using your hands to gesture. If possible, remove your glasses or wear contacts as the lens may cause a glare. However, if your vision is so bad that you will be squinting, definitely leave the glasses on!

CLOTHES MAKE THE INTERVIEW

- ✓ Avoid shiny, bright, or otherwise distracting clothes
- ✓ No funny ties or short skirts
- ✓ Leave the large jewelry at home
- ✓ Remove glasses or wear contacts, if possible
- ✓ For women, apply slightly more makeup than usual. For men, allow the professional make-up artist to apply foundation

WHAT TO BRING

Always make an effort to bring a press kit. Especially include materials such as your report on the uninsured and a one page executive summary. The producer may ask the graphics department to adapt some of your charts and graphs to be shown on air.

You may also want to bring one page of notes with you. While you don't want to be reading from notes, if you do have specific points you want to make you should feel free to have them handy.

The reporter may wish to interview someone in the community who is uninsured. If you have someone who would be willing to speak, bring his or her name and telephone number with you. (For more information about gathering stories, see the July 1999 ImPRESSive, "The Art of Storybanking.")

FOLLOW THROUGH

Once you have finished, thank the reporter for his or her time. Make sure he or she has your business card for future reference. Find out when the interview will air and ask for a copy of the interview, if possible.

If you cannot get a copy of the tape from the station, make sure to record it yourself. Review the tape to see how you might improve for future interviews. You can also use the tape for soliciting possible funders or showing your board of directors.

CONCLUSION

Despite the amount of preparation involved, television interviews are very important to master. The more time you take perfecting your message and "stage presence," the more likely you'll be asked back to do more interviews on health care topics. Many people clamor to do television interviews and then don't do the preparation necessary. As a result, they end up looking stiff and unnatural. You can always spot the television novices; they stare into the camera like deer in your headlights and barely manage to raise their voice above a whisper. You can bet they won't be asked back. Producers love to find people who are knowledgeable about their subject are and give good interviews. This is definitely the reputation you want to cultivate.

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ImPRESSive

A MEDIA TIP SHEET FOR ADVOCATES

Families USA ı June 2000

Getting Your Message into National Stories

You have a golden opportunity. A major national news organization is running a story on one of your issues. Your local media will likely carry the story in the next day or so, but you're not sure how you can get your group into that story.

Mention of your group in the national story would benefit your work in many ways. First, the story is going to raise awareness of the issue on a national level. This will lend credibility to the importance of the issue and may help to speed you toward your goals.

Second, the story gives you an opportunity to raise your organization's profile and increase name recognition.

Third, the story could help coalesce local efforts and focus the goals you and your coalition are seeking.

THE ISSUE

Your group, Citizens for Affordable Prescriptions (CAP), has been working to raise awareness of the high cost of prescription drugs. You've done the background work. You've talked to senior and disability groups and collected information about how much they pay for prescription drugs. You've collected stories from them illustrating the magnitude of the problem. You have the names and phone numbers of at least seven seniors and three young to middle-aged people with disabilities who are juggling prescription drug costs and necessities like food and rent. They're willing to talk to the media and are knowledgeable about the overall issue.

You've already laid the groundwork for a successful media campaign. In the past, you've made efforts to talk to the media, but have been rebuffed. You've talked to reporters at the major newspaper, radio, and television stations. They've been interested in the story, but have been unable to get the go-ahead from their news directors or editors.

You've written and submitted op-ed pieces and pursued editorial boards. While you've been given a hearing, there wasn't much enthusiasm from any of the people you met.

You have an up-to-date media list of reporters' e-mail, fax and phone numbers and their organizations, just itching to be used. But before you can use your resources and connections, you have to know the story is coming.

HOW DO YOU FIND OUT ABOUT THE STORY?

Keep in Touch with Other Organizations

A national group might notify you that they are planning a major press event on your issue. It could be they are releasing new data or they are reacting to newly-introduced legislation that affects your state.

The national group could also know that an important reporter is working on a story about the issue. The national group would know this either because the reporter has contacted the organization for quotes or information, or because the national group provided the reporter with newsworthy data and got a solid commitment to run a story.

Follow the News

Another way to keep tabs on current stories is by following the "newswire". The newswire is breaking news. Do you remember in old movies how people used to watch the "ticker"? Well, that's the newswire, the front line of the news business. It's now computerized, but its function is still the same. The newswire is a round-the-clock operation. Reporters for the newswire can get stories out almost immediately; they don't have to wait for the next day's edition of the newspaper or the morning news. Nearly every news organization subscribes to one or more newswires. The newswire is fast and easy and the lifeblood of small newspapers and radio and television stations.

The most important such service is the AP newswire. The websites of most large papers offer a link to the AP wire, as does the website www.commondreams.org. While the AP does have its own website, it is not very user-friendly.

The AP newswire is updated constantly throughout the day and night and is a great resource. Other major news services are Reuters, Knight-Ridder, Bloomberg, and the New York Times.

Why is the newswire so important? Well, most local media don't have the resources to keep large staffs. They need a tool that will help them keep on top of breaking news without having a reporter in every corner of the world. They will have a staffer watch the wire and notify the news director when important news hits. Stories can also be lifted, with attribution, directly from the newswire and put in the newspaper. It's the cheapest, easiest way for local media with small budgets to maintain their newsworthiness.

At the same time, media can lift essential, national information from the newswire, then tailor the story to their readership by including local information in the story—for example, how the high cost of prescription drugs is affecting area residents. Your group could get a quote about how seniors are being price gouged by the pharmaceutical industry. Or, if you're really lucky, you can get an entirely separate story—called a sidebar—uniquely addressing local people (remember your seven seniors and three disabled spokespeople?) and their situations. This story will hopefully include your group's suggestions for how to resolve the problem.

If you have internet access and an intern to spare, you can watch the wire for relevant news. Watching the AP wire by logging onto a website a few times a day can be a simple way of monitoring media coverage of health care issues. On the Yahoo or AOL websites, for example, you can set up a default homepage that tracks the AP and Reuters. Every time you log on, you can be monitoring the newswire. Still, not all organizations have the resources to do this.

What Is A "Sidebar"?

A sidebar is a related story that provides additional information augmenting a larger story. You can help get a sidebar by providing:

- Local data supporting the national story
- Quotes from local health care consumers and organizations
- An event or photo opportunity

If monitoring the newswire doesn't seem feasible, your group will have to rely on your personal relationships with reporters and editors. As advocates, these relationships should always be a high priority. Good relationships with the media are instrumental to good press coverage of your group and your issues.

It's a good idea to put together a press kit about what your organization does and what its goals are and then meet with reporters, news editors, and editorial page editors. Familiarize them with your organization and make sure they have your contact information. Let them know that you have real people they can interview. If you have a good relationship with your local reporters and they're familiar with you and your group's issues, they may tip you off to a breaking story and ask for your comments. This is the best situation to be in because it means your group already has a relatively high profile in your community. If you're not at this stage yet, there are still plenty of things you can offer reporters.

What Should You Do?

Now that you know the story is coming and you've got some connections at your local media outlets, you have to start working the phones and e-mail. Knowing the story will be on the wire gives you an advantage. Make your calls to friendly reporters and tell them you've heard there's a story about prescription drugs coming out over the wire. Offer them your resources and expert information to localize their story, and offer to provide them with one or more people to interview. This is called "putting a face on the story."

What Are Your Resources?

Tell reporters you know real people who would be willing to talk about their prescription drug costs. Real people help humanize the issue and make it more interesting to readers and reporters. You need to have sympathetic examples, too. Be sure to stop and carefully think about who is the most likely person to generate support for your issue.

In addition to providing reporters with health care consumers, consider asking sympathetic health care providers to speak out on the issue. If you have a relationship with a local pharmacist, ask if he or she would be willing to talk to reporters. Doctors and nurses are also respected sources for reporters.

Provide reporters with any local data you might have. The national story addresses the big picture, but what people reading their newspapers over a bowl of cereal and a cup of coffee want to know is: how does this affect me? If you can prove that it has an impact on their parents, their neighbors, friends, and possibly themselves one day, then you will have done 80 percent of the work. Readers and reporters need to see the issue in terms of their own backyards before they'll really sit up and pay attention.

Think about organizing a media event. If you've gotten your information off the wire, this is probably too ambitious considering your time constraints. Depending upon when the story appeared or how you got the information (from the national group or the newswire) you might have a couple of days in which to schedule a small event at a senior center where seniors can show off the quantity of prescription drugs they consume and provide testimonials.

You could also organize an event at the local pharmacy and have consumers and a pharmacist available for pictures and interviews. If the national group informed you a few days or even a week ahead of time, then you've got enough time to throw together a good visual for the evening news or a nice picture for the morning edition. Some examples of good visuals would be a senior citizen holding up the prescriptions he or she has been unable to fill due to cost, or surrounded by his or her prescription drug vials, or a senior standing at the cash register at his or her local pharmacy.

The best thing you can do, after making your all-important phone calls, is to provide reporters with a press release about the issue. You should have bullets detailing the information you've accumulated on prescription drugs in your area and a soundbite—which is a short, attention-grabbing quote—that may be included in a story.

Detail the three or four most important things that reporters should include. Make them newsworthy. For example, the bullets could look like this:

- From January 1998-January 1999, prescription drugs in Generic County rose 2.5%
- From January 1998-January 1999, Social Security and Disability payments in Generic County rose 1.9%
- Three out of four Generic County seniors have admitted not filling necessary prescriptions due to cost.
- 4,000 Generic County seniors are taking three or more prescription drugs a day.

Include a quote from your spokesperson in the release. "Generic County seniors are bearing the burden of the highest prescription drug costs in the industrialized world. They're paying more than Canadians, Vets, and pets!"

Make sure to provide contact information and be available to reporters at all times. If you're serious about getting some mileage out of a national story, you need to be reachable. (For more information on how to write a good press release see the October 1998 *ImPRESSive*).

Make sure you have the names and phone numbers of the seniors and disabled people who would be willing to talk to reporters.

What Can You Expect?

Okay, you've done a lot of work. You've talked the ear off every reporter in your area with an interest in the national story. You were pressed for time, so you couldn't manage an event, but you did put out a readable, newsworthy press release with clear contact information.

In a perfect world, a story profiling your group and the work it does to promote the interests of seniors with high prescription drug costs would hit the front-page of the newspaper the next day.

In an imperfect world, the newswire story runs and there's a sidebar on your most likable senior spokesperson, Mrs. Amelia Armstrong.

In a really imperfect world, the newswire story runs with no mention of you, your group, or Mrs. Armstrong.

Don't Throw in the Towel

If you didn't get any media attention for your group even after all your efforts, be comforted. Taking time to familiarize the media with your group and your issues is never wasted. At the very least, you're laying the groundwork for future stories. You've got to regroup and remember your assets. A national story on prescription drugs ran in your local newspaper; that still puts you two steps ahead of where you were. Now it's time to exploit that window of opportunity.

Invite the folks at the neighborhood senior center to write letters to the editor about the prescription drug story. Encourage them to describe their own experiences and congratulate the paper for running the story.

Write an op-ed piece with all that great, specific, local data. Keep it short (under 700 words) and encourage another group working in your issue area to co-sign it with you. Doctor, nurse, and pharmacist groups would be credible allies and help attract more media interest. Given the recent national story, you are much more likely to get your op-ed published.

Set up the round of editorial boards and go over it again. Be persuasive and persistent. Use your data, your anecdotal information and be sure to remind them of the national story their own newspaper recently ran. (For more hints on op-eds and letters to the editor, see the March 1999 *ImPRESSive*).

NOTE: Newspaper strategy is emphasized because plenty of small to mid-sized radio and television stations still look to newspapers to help them develop the news. An editorial or a front-page story in the newspaper will almost certainly get some attention from radio and television reporters.

CONCLUSION

It's unrealistic to expect consistently good reporting on your issue without a lot of legwork reaching out to the media. While it's not unheard-of for groups to luck out once or twice, nothing can replace a friendly, mutually beneficial relationship with reporters.

A national story can give you a strong bump onto center stage, but it's not going to last unless you have a mapped-out media strategy, clearly-defined long-term goals, and a commitment to earning the media attention you seek.

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Concord Monitor
Editorials

Thursday, August 30, 2001
Editorial: Let him speak

***A controversial thinker deserves civil treatment in Concord.**

The Governor's Commission on Disability is under attack for inviting a provocative and unpopular thinker to a Concord conference on genetics and bioethics. But such boldness is to the commission's credit. There is nothing to fear in Peter Singer's appearance but the fear of ideas.

Singer is a Princeton professor who has been described as "the most influential ethicist alive" and "the world's most reviled philosopher." He has earned these monikers, among others, by climbing aboard trains of thought that are offensive to others and riding them all the way to the station.

Consider this observation from Practical Ethics, one of Singer's two dozen books: "Killing a disabled infant is not ethically or morally equivalent to killing a person. Very often it is not wrong at all."

Or this, from Rethinking Life and Death: "If disabled people who must use wheelchairs to get around were suddenly offered a miracle drug that would, with no side effects, give them full use of their legs, how many of them would refuse to take it on the grounds that life with a disability is in no way inferior to life without a disability?"

Extracting such quotes from Singer's writings is unfair, because it strips them of context and nuance. And yet there is nothing to soften the edge of his most basic belief: Life has no value without self-awareness. This outlook leaves Singer defending a stray cat's right to life while questioning that of an infant born with Down syndrome.

Not surprisingly, Singer is loved in the animal rights movement, loathed in the disabilities rights movement and, perhaps, misunderstood to one degree or another by both.

One Monitor letter-writer equates him with Hitler, yet Singer lost three grandparents in the Holocaust. Though assailed for his cold-heartedness, the goal he advocates is to reduce suffering of all kinds in the world.

One advocacy group, called Not Dead Yet, is protesting the prospect of Singer's appearance in New Hampshire; it protested his appointment at Princeton as well. Republican gubernatorial want-to-be Bruce Keough has called on Gov. Jeanne

Shaheen and the disability council to rescind the invitation.

They should not. Singer should be heard - and challenged, as he will be, by his audience and fellow speakers alike. Beliefs are like muscles; without exercise they grow flabby. Singer's appearance will invigorate what is an essential debate of our time, one that advancing technology forces us to confront.

As he once wrote: "Our increased medical powers mean that we can no longer run away from (questions of life and death) by pretending that we are 'allowing nature to take its course.' In a modern intensive care unit, it is doctors, not nature, who make the decisions."

Some have assumed that the commission's speaking invitation amounts to an endorsement of Singer's ideas. It does not; indeed, the commission's director speaks of the need to confront them.

Others fault the commission for providing Singer with a forum and his ideas with recognition. That's absurd. He is a renowned academic. His books have been translated into 15 languages. You could paper a concert hall with Web pages that debate his writings.

This is not the first time a commission conference has been designed to air a controversy that is unsettling to those it serves. Two years ago, its program on physician-assisted suicide included speakers on both sides of the issue. The participants included members of the very advocacy group that now opposes Singer's invitation.

Long ago Singer was shouted down and even assaulted at some appearances. But he is entitled to express his views, and when he does so in Concord on Oct. 5, he should be treated with civility.

As for his ideas, they will rise - or fall - on their merits.

Nazi 'principles'

Wednesday, September 5, 2001

Letter to the editor: As a board member of Not Dead Yet, I am writing to clarify some highly debatable statements in your editorial on the Peter Singer controversy.

You glibly dismiss any comparisons between Singer and the ideologies that resulted in the extermination of some 250,000 people with disabilities in Germany. In fact, Holocaust scholar Michael Burleigh pointed out that Nazi propaganda - and eugenics literature predating the Nazi regime - promoted the idea of euthanasia based on both "humanitarian" principles and utilitarian ideals. Burleigh noted that these are the same principles and ideals Singer uses to promote his own agenda. The fact that Singer's grandparents were victims of the Holocaust has no relevance to the issue of comparing his own ideologies with those that lead to the German extermination program of people with disabilities. But it seems fair to say that Singer regards the murder of his grandparents as a greater crime than the killing of people with disabilities at the hands of the Nazis. We believe the murders to be equally heinous. We remember our history, even if Michael Jenkins, Peter Singer and the Monitor editorial staff don't.

TOM CAGLE Henniker

No science behind Singer's agenda

By Stephen Drake

Wednesday, September 5, 2001

Letter to the editor: Your editorial on the Peter Singer controversy contains so many inaccuracies, distortions and plain muddled thinking it is hard to know where to begin.

First, you suggest that Singer is "misunderstood" by the disability rights movement. This is a patronizing and unwarranted assumption. Many of us have read more of Singer's work than anyone on your editorial staff. Not Dead Yet has issued comprehensive analyses of his works that relate to disability. I have taken Singer on in an NPR show aired in Philadelphia. We understand his work and what he stands for all too well. Singer asserts that it should be legal for parents to have newborns with disabilities killed within the first 28 days after birth. A less often noted assertion of Singer's is that people with cognitive disabilities of any age should be killed by medical professionals if they don't meet Singer's criteria for personhood and if the family or legal guardian wants it done.

According to Singer, individuals who don't qualify as "persons" should be denied constitutional protections to due process and equal protection of the law. This public policy proposal would affect thousands of New Hampshire citizens with

Alzheimer's, mental retardation and other cognitive disabilities. Singer builds his case in much the same way Charles Murray and Richard Herrnstein did in The Bell Curve, a notorious bestseller that claimed to "prove" that people of African descent were intellectually inferior to Caucasians. The book was an attempt to legitimize and normalize racial inequalities. It was a political agenda masquerading as science. Singer promotes his ideas the same way. He uses disability-related research selectively, ignoring anything that interferes with his agenda. When supporting research can't be found, he resorts to unsubstantiated assertions. Given that the Monitor is likely to revisit this controversy in the future, I hope you will give disability activists at least as much respect as you have shown for Peter Singer. At least do us the courtesy of accurately recounting our perspective.

STEPHEN DRAKE Forest Park, Ill.
(The writer is a research analyst for the group Not Dead Yet.)

Thursday, September 6, 2001

Keep the Fox Out
By Gail McLeon

Letter to the editor: I write concerning your stand regarding the decision by the Governor's Commission on Disability to invite Peter Singer to New Hampshire. In your editorial, you suggest that it is appropriate for the commission to invite Singer to one of its events.

I would travel some distance to confront Singer concerning his viewpoints at an ethics conference or medical convention, but inviting him to address a gathering hosted by members of the disability community is a mistake. This implies acceptance and respect for his views by the disability community itself. Singer advocates the legal extermination of people with advanced Alzheimer's, profound mental retardation and other cognitive disabilities. Singer promotes the idea that these are "non-people" and that the idea of extermination is good public policy. Would you give your support to a government-sponsored holocaust remembrance event that invited members of Aryan Nation to defend the actions of the Nazis against the Jewish people? Since you find Singer worthy of respect and civility, I shall expect to see a future editorial calling on the Human Rights Commission to host exactly this sort of an event. Seems a bit like asking the fox to address a gathering in the hen house.

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Article published February 25, 2002
Kennedy kin urges disabled not to give up

Kennedy: voice for disabled. (ASSOCIATED PRESS)

By STEVE MURPHY
BLADE STAFF WRITER

BELLEVUE, Ohio - The roots of Ted Kennedy, Jr.'s, career as a health-care lawyer and advocate for the disabled go back to the day in 1973 when his father told him he would lose part of his right leg to bone cancer.

Lying in a hospital bed, the 12-year-old boy thought that meant doctors would cut the cancer out, leaving him with two intact legs. No, Sen. Ted Kennedy (D., Mass.) told his son; they'll have to amputate part of the limb.

"I was shocked and horrified when I heard those words," the younger Mr. Kennedy said yesterday during a visit to Bellevue Junior High School. "Somehow I was infused with the idea that living with a disability was worse than not living at all."

Such attitudes are the biggest hurdle faced by people with disabilities, Mr. Kennedy told an audience of more than 500. Neglect, pity, and discrimination stop millions of people from working, living on their own, and using public transportation, he said.

"In this country, 70 percent of people with disabilities who are willing and able to work can't get a job. ... The social isolation for many people with disabilities is profound," he said. "People with disabilities deserve the same rights as everyone else."

The Americans with Disabilities Act, passed in 1990, has helped provide some of those rights, especially in easing access to schools and other public buildings, Mr. Kennedy said. "I think the Americans with Disabilities Act is an incredible civil rights document that affects 40 million people," he said. "I think it's been successful. ... There are ramps in front of this school. Why? Because of the Americans with Disabilities Act."

But many employers remain hesitant to hire people with disabilities, because they fear being sued under the law, Mr. Kennedy said.

Part of the problem is that people with less serious medical and psychological conditions have used the act to seek accommodations from employers, he said. "Does anyone think the Congress of the United States debated for five years ... to protect the civil rights of people with lower back pain?" he said. "That's not what they were doing."

Mr. Kennedy said he struggled with feelings of shame and embarrassment during and after his battle with cancer.

His chemotherapy treatments caused his hair to fall out, and he was appalled at how his prosthesis looked.

He recalled waiting during swim classes at school until everyone else left the pool. "I was very ashamed of my personal appearance," he said. "I thought no girl in the world would want to go out with me. ... It took me years to process how I felt."

Mr. Kennedy said he went skiing on his rebuilt leg "to keep up with my family" and still enjoys the sport. He predicted that as people live longer, senior citizens will face many of the same issues as those with disabilities. "Access to restaurants and movie theaters will be even more important, because people will be living longer with mobility impairments," he said. "The real question is, how much are we going to pay for all of this?"

Mr. Kennedy spoke yesterday as part of a benefit for Bellevue Hospital's Cancer Care Program, and he urged his listeners to support the hospital and its foundation.

Discussing trends in health care, Mr. Kennedy predicted passage of a federal patients' bill of rights within the next year.

"There's a Republican bill. There's a Democratic bill. You can probably guess which one I think is the better bill," he said, drawing laughs from the audience.

Thanks to the Internet, patients can find much more information about diseases and treatment options than they used to, Mr. Kennedy said. "Twenty years ago, people did what their doctor said to, without question," he said in an interview before his speech. "It's not like that anymore. People are empowered consumers."

Mr. Kennedy has been executive director of a nonprofit advocacy and public policy office on disability-related issues and a teaching fellow on disability policy at Harvard University's John F. Kennedy School of Government.

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Posted on Sun, Apr. 21, 2002

Leaving out barriers, but not amenities

By Alan J. Heavens

INQUIRER REAL ESTATE WRITER

Eleanor Smith of Decatur, Ga., remembers what life was like after polio forced her into a wheelchair in 1947, at the age of 3. "In my small town in Illinois, because there were no curb cuts, I would be going down the middle of the street with my little friend pushing me," she said. "If I wanted up, we went up a driveway and back into the street."

When she was older and wanted to go to the library, "there were at least 10 steps going up the front, and my friend had to come out carrying a stack of books from her chin down to her waist," Smith said, "and I would make my choices."

The supermarket was the only store Smith could enter. At every other store, "they had to bring things out to show me." It's a different world today. Every new curb has a curb cut. It would be unthinkable for public buildings not to be accessible to everyone.

Yet most private housing remains inaccessible to people with physical disabilities. That's because the Americans With Disabilities Act, the 1973 Rehabilitation Act, and the Fair Housing Act deal more with multifamily buildings - rentals, condos and townhouses - than with single-family homes.

"Whenever I went to visit friends, I either was stopped at the front stairs [or] if there were no stairs, then the visit ended at the bathroom," Smith told a seminar at this year's International Builders Show in Atlanta. So she decided to work for change. But Smith thought it necessary to look at the problem not from the perspective of housing for the disabled, "but just as housing."

She and others decided that such a change could be made more easily in new construction, but that for builders to accept change, "we had to keep the list short." A disabled Japanese architect with whom she discussed her ideas said the British already had a word for it - visitability (and laws requiring it in houses built after 1998).

"Simply, it means having one no-step entry to the house - in the front, the side or rear," said Mary Jo Peterson of Brookfield, Conn., a design consultant. "All interior doorways should be a minimum of 32 inches clear. And there should be a first-floor bathroom with such a doorway."

This does not mean a 32-inch-wide door. That would provide less than 30 inches of clear space - not enough for a wheelchair to get through without scraping. To provide enough clear access, the door would have to be 36 inches wide.

Although Smith has used a wheelchair for most of her 59 years, her concern is also for those who find themselves in her situation at the end of an active life without any barriers. "You become physically disabled, and you are no longer in the bridge club or serving on committees," Smith said. "It is life-changing."

Visitability is not a question of amenities. It means ensuring physical safety and avoiding the humiliation disabled people often endure when they cannot overcome physical barriers to do everyday tasks. "People have lives, and, of course, it does matter if you can get through your own doors, but it also does matter if you can visit your child, or your grandchild, or your best friend," Smith said.

By 1992, she and her group, Concrete Change, were able to persuade the City of Atlanta to adopt an ordinance requiring that all new construction using federal and state funds have these visitability features.

The visitability ordinance in Austin, Texas, has two additional requirements involving placement of light switches and a 36-inch-wide level route through halls and passageways in single-family housing built with state funding. A Texas law, effective in 1999, changed building codes to require such changes in all single-family affordable new construction.

Georgia passed a similar law in 2000. Puma County, Ariz., which includes the retirement destination of Tucson, adopted a comparable visitability ordinance in February, as did Urbana, Ill., south of Chicago. Florida's "bathroom law," adopted in 1989, requires that single-family houses, duplexes, triplexes, condominiums, and townhouses provide at least one bathroom on habitable grade levels, with a door that has a clear opening.

The National Association of Home Builders, through its Seniors Housing Council, is trying to get its membership to voluntarily incorporate visitability standards in new housing. But, Peterson said, the issue can raise conflict because builders, already squeezed by high construction costs, don't want to take on more if buyers don't specifically request it. She argued that visitability is an idea that includes everyone, even parents with strollers that need to be pulled up and down front stairs.

"It integrates people of all shapes and sizes," Peterson said. Visitability fits into the concept of universal design, behind which is a philosophy that takes two trends into account: That people 45 and older buying trade-up housing don't plan to move every seven years, which has long been the national average. And that as people age, they will progressively have trouble doing everyday tasks, such as reaching down to open a kitchen drawer, reaching up to get a book on the top shelf of the bookcase, or stepping over the raised base of a shower stall without having something to grab onto.

Universal design incorporates most of the ADA and Fair Housing Act design and accessibility guidelines because, over time, they allow a consumer to grow into a house. As with visitability, builder objections center on cost and consumer perception. "Builders react to market," said Ed Phillips, president of the Georgia Association of Home Builders. "But when we are able to look past the issue of disability to one of the couple with twins who need to maneuver a stroller, or my bad knees, or my 82-year-old father coming to live with me someday, then the need for visitability becomes something affecting all of the market."

It is much less expensive to adapt new houses to visitability standards. The California Foundation for Independent Living Centers said that a zero-step entry for a new house costs $150, while wider interior doors cost $50. "At $200, visitability amounts to about a third of the price of one bay window," the foundation said. To retrofit older houses, conservative estimates of the cost of a zero-step entrance is $1,000, while widening an existing doorway is as much as $700, according to estimates supplied to the foundation by the NAHB.

Housing in older cities such as Philadelphia is at a definite disadvantage. "None of these houses are handicapped-accessible," said Christopher J. Artur, broker/owner of Artur Realty in the city's Mayfair section. Artur said he sold a house a few years back to a woman with multiple sclerosis. One of the few in the Northeast that could meet her needs was a one-story bungalow rowhouse in Wissinoming: "The house had no basement and no garage, and there were no steps from the street to the front door."

"Since none of these houses are handicapped-accessible, people are asking how they can be adapted to their needs," Artur said. "That question is going to be asked more and more as people here age."

Philips said that for many years, builders in Georgia, faced with calls for accessibility, "responded not just no, but 'hell no'." "About three years ago, rather than 'hell no,' we started saying, 'We might be in favor of that if . . .' instead," he said. "We decided that it was better to be part of the process, where we could get things done without having to drag it to the state Capitol." Philips met Smith for the first time when she was part of a group blockading the builders' association office, holding a sign that read, "National Association of Hypocritical Builders."

The office became accessible shortly after. "Incorporating visitability into residential construction is an opportunity to make a difference, but a profit as well," Peterson said. "And the profit is to be made by those who are there first."

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Disability rights groups rally at Capitol

By *Sarah Shipley (Daily* Texan Staff)

March 22, 2002

More than 20 disability rights organizations met Thursday at the Texas Capitol to support a lower court's ruling that allowed the state's hospitals to administer treatment to premature babies without parental consent.

The case, slated for an April Texas Supreme Court hearing, began when Mark and Carla Miller accused Houston's Texas Women's Hospital for administering treatment in 1990 to their premature daughter, Sidney - treatment the couple said caused their daughter to develop cerebral palsy.

But Mark Bono, an attorney for the Hospital Corporation of America, the parent organization of TWH, said one of the core questions in the case is whether the parents gave consent for resuscitation.

"It is shown in the doctors' notes ... that there was consent for resuscitation," Bono said. "The doctors, by ethical code, give medical attention. The plaintiffs later sued for giving Sidney support. We say that is ridiculous. We are not going to let any child die at the hospital."

David Keltner, an attorney for the Millers, said the attending physicians informed the couple that treatment administered would cause irreversible damage to their daughter. Keltner added that the Millers chose not to accept the treatment because they didn't want to cause their baby pain.

"What they are suing for is that the hospital, over objections, administered treatment that caused horrible damage to the child," he said.

But disability rights organizations said the case centers on discrimination. Bob Kafka, a member of Not Dead Yet, a disability advocacy group, said all life should be valued regardless of disabilities.

"We feel that once a child is born ... that the individual has the right to live with whatever the quality of life," Kafka said. "The level of disability is not as significant as the idea that children with disabilities need to be valued in society. And that starts after they are born."

The rights organizations filed an amicus curiae, a brief issued by people who wish to advise the court on a case, but who are not direct stakeholders.

Sidney's father said the arguments presented Thursday by the rights groups were wrong and believes Hospital Corporation of America has organized the brief to pressure the court.

"We are confident that the court will withstand pressure and consider this case on the laws and its merit. Nothing we advocate would justify mercy killing of any disabled persons or an abortion for a compromised fetus," he said. "[My wife and I] could have aborted Sidney in their hospital, and we chose not to."

Colleen Horton, a children's policy specialist with the Texas Center for Disability Studies and parent of a disabled child, said the case is a reflection of the situation of all children with disabilities.

"It's about allowing arbitrary decisions about which child gets to live and which child will die," she said. "The decision of the Texas Supreme Court will not simply be a reflection on Sidney's life; it will reveal how we value the lives of all of our children with disabilities."

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March 24, 2002

Life Span Is Nearly Doubled for Down Syndrome Sufferers

By THE ASSOCIATED PRESS

An extensive study of Americans with Down syndrome has found that they are living twice as long as they did two decades ago, though still not nearly as long as other Americans, government researchers say.

The scientists, from the Centers for Disease Control and Prevention, studied death records of 17,897 people with Down syndrome from 1983 to 1997. The average age at death rose, to 49 in 1997 from 25 in 1983. In that time, the average age of death for other Americans also rose, to 76 from 73.

The reasons for the sharp increase in life expectancy are not fully known. But the study, which was reported on Friday in the British medical journal Lancet, noted that cancer was not listed as a cause of death for people with Down syndrome as often as for other Americans.

The study found that malignancies other than leukemia and testicular cancer were reported 93 percent less often for people with Down syndrome than for people in the comparison group.

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02/25/02

Wayne Dawson: A view from the chair

By Charles Cochran

Savannah Morning News

Wayne Dawson was a 17-year-old farm boy, swimming with friends in a river when he did something that set the course for the rest of his life: he dove head-first into shallow water.

The accident broke his neck, leaving him in a wheelchair.

"I tried to put a little bit too much of me into too little water," he recalled.

But given the opportunity, Dawson -- the 42-year-old executive director of the Savannah-Chatham County Fair Housing Council -- says he wouldn't change a thing.

That's how much he values what he's learned, observing people from the perspective of a chair.

He relishes the passion he has acquired for fighting discrimination, born of being told to take his chair to the back of restaurants.

Of being told -- as he was when he moved to Savannah in 1994 -- that there was no room in an apartment complex for a man in a chair.

In 1990, Dawson's passion led him to the South Lawn of the White House, where he watched the elder President Bush sign the Americans With Disabilities Act. The federal law established new civil rights for the disabled, requiring that newly built homes and office buildings be accessible to anyone in a chair.

Dawson hates discrimination. He fights it every chance he gets. That is what the chair has given him.

Q. If you could cure one terrible disease, what would it be?

A. "To me, intolerance is a disease. When people treat people differently because of the way they look, that's a disease -- and I don't understand that. I didn't understand it when I grew up in eastern North Carolina; we'd drive up to Raleigh and there'd be a sign up there, 'This is Klan Country.' My parents tried to explain it to me, but I didn't understand it then and I don't understand it now."

Q. What one word describes you most and why?

A. "Can I tell you the word I don't like used? Maybe it'll help me get to the word I'd like used. People say sometimes, 'You're an inspiration.' But I don't think I'm an inspiration, and I don't know that I want to be thought of that way.

"If people see something good that I do and they want to emulate it, that's fine -- but I don't fall into the class of those dreamers that I try to emulate. I'm just going about living my life. I'm like everybody else: I've got problems like everyone else has got, no more or no less."

Q. What is your best feature physically?

A. "It's definitely not my coordination. I grew up as a clumsy walking person, and now I'm a clumsy person who uses a chair. So it's definitely not grace, I can tell you that. I've been told that my best physical feature -- the way people remember me sometimes -- is my eyes. My grandfather has blue eyes and my father has blue eyes, so I can't take a lot of credit for them. I just came by them naturally."

Q. What is the one misstep or mistake you would correct in your life if you could?

A. "Most people would probably think, 'Well, I'll bet you wouldn't dive into the river like you did and break your neck, would you?' But I don't know that that's the case.

"I have to tell you: I've seen a whole different side of people from the chair. The view from behind this wheel is totally different than it was when I was walking around. It's like the poem: I took the road less traveled.

"You know, there are some people who will say that they're your friends, and they're there just as long as the weather is good. But let things get a little tough, and they're not beside you any more.

"So, I get a chance to see a side of people that not a lot of people get to see. I think that's one decision I definitely wouldn't change."

Q. What would be your ideal last meal?

A. "I think it would probably be either Greek or Cajun. A good friend of mine who was Greek used to run a restaurant in eastern part of North Carolina ... Once at a party, he cooked this lamb -- a real lamb, not a gyro but real lamb. This stuff would melt in your mouth. He baked some potatoes, some Greek meatballs, and pita bread. Oh, I love it.

"I also love all the seafood that goes into Cajun dishes. A friend of mine from college was an instructor at LSU, and he said one time: we're going to make jambalaya -- and your job is to make the roux.

"You put a little bit of olive oil in a frying pan, put it on low heat -- and you begin to dump flour in it, and move it around, and move it around. Forty-five minutes after I started making the roux, we were almost there. My arm was about to drop off -- but we almost had a good roux, according to him.

"When I eat Cajun now, I go to Huey's or Creole Red. I don't make roux any more."

Q. If you were stranded on an island (one with electricity and a CD player, of course) and could only bring five CDs, what would they be?

A. "I'd have to bring James Taylor. I'd probably take the Eagles. I'd have some sort of blues compilation -- the old Muddy Waters and John Lee Hooker type stuff. I'd probably have some kind of jazz assortment. And I guess if you were going to be on an island, somebody would throw you off if you didn't have a little Jimmy Buffett. You can't go to an island without Jimmy Buffett.

"I actually had tickets to see the Eagles while I was living in Charlotte, and they canceled twice. Over the course of about a year, I moved down here (to Savannah), so I had to drive four hours to get back up there for the concert.

"During the trip back up there, I had gotten just about to Columbia, S.C. -- still over an hour's drive from the concert -- when my van's hand controls fell off.

"I had given a friend a ride back up to North Carolina -- well, she's blind. So imagine this sight: you've got a guy driving a lift-equipped, hand-controlled van, and a blind lady who's having to reach over and press the accelerator.

"We were driving around Columbia, trying to get back up to Charlotte. I was steering, and she was leaned over and accelerating. And you know: she did real well. She didn't know how far to press the lever that operates the accelerator, but the brakes were working. Once she got up to around 75 I said, 'I think you can probably ease back a little bit now.'

"We made it safely; we made it just fine. We were actually able to get it repaired up around Columbia, so I was able to drive on up to Charlotte.

"My girlfriend (who was already in Charlotte) was tied up in traffic. I was surprising her with the tickets. The surprise almost ended up being on me because we almost didn't make the concert.

"When she pulled in, she saw me and said, 'It's so good to see you.' And I said, 'It's good to see you, too. Hop in the van.' We drove up to the concert, then parked and went inside where the concert was a few minutes late starting.

"We had second-row tickets. The lights went down just as we got seated. It was one of those things that will never happen again -- and it was a fantastic concert."

Q. If you could be anyone in history, who would it be and why?

A. "I would like to be someone like (U.S. Rep.) John Lewis. I went up to Congressman Lewis' office, and I literally felt like I was in a shrine. There were pictures of all these people he had met and had worked arm in arm with to bring about civil rights for a lot of folks. I just have a tremendous admiration for him and the work he's done.

"That's the kind of person I'd like to be; I probably fall far, far short."

Q. If you could be any super hero, mythical creature or cartoon character, who would it be and why?

A. "I guess I'd like to be Bugs Bunny. You get the pleasure of out-smarting fate. I kind of like the challenge. I don't have to do everything for myself, but I kind of like to be in control of the way things get done."

Government reporter Charles Cochran may be reached at ccochran@savannahnow.com, or at 652-0396.

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February 24, 2002

Disability activism is good news
By MICHAEL VOLKMAN

I am not the first person to have a regular column that focuses on disability issues in a daily newspaper. But ! am the first one doing it for this newspaper.

Is that such a remarkable accomplishment? The column is not as ubiquitous as some of the ones that run two or three times a week. It usually runs once per month. That's about right for what my themes are, because they mostly have relevance to things that are in the background of our daily lives rather than to fast-breaking news events.

It's one small step, but it's a giant leap, too.

The oft-repeated statistic is that the U.S. Census Bureau estimates that there are 54 million Americans with disabilities. This would mean that this is the largest minority. It is also the most diverse minority, because it cuts across all other minority groupings of ethnicity, age, race, sex and economic class. We are not all of one like mind, so it is impossible to represent everybody in this minority.

In fact, it is probably true that most people with disabilities don't consider themselves to be well-connected to the disability rights movement, which is a loosely defined network of advocacy organizations and publications. Many probably don't know there's such a movement.

I was unaware of its existence as a movement until I got a job working for it. I had known some of the people who were part of it without realizing the scope of what they had helped to build. Becoming a part of it includes an important change in the way one thinks about disability. It is no longer about health or loss or inability. It is about politics and power.

When you read about disability in a newspaper, you usually see it in two contexts. One is science and health. Stories highlight research studies that aim to provide understanding or to attempt some corrective action to the body. The effect of this is to reinforce a view of disabilities as medical problems to be solved. The other is human interest. A person or group will be profiled for something they are doing "in spite of" their disabilities, or the story may describe how they live, with subtle emphasis on the disability and how it contributes to a diminishment of wealth or happiness. The latter show up more frequently during the holiday season.

On rare occasions, disability does manage to make its way to the hard-news section, maybe even the front page. This often happens, as it did here in Albany three weeks ago, when a bunch of angry protesters made a big fuss at a government building, crowding lobbies and hallways that are too small for a great number of people in wheelchairs.

It is important for you to see us as hard news. We can accomplish the freedom and equality that we expect as Americans when we present ourselves the way we want to be presented. If you don't have a disability yet, it is important to see the issues that matter to us are political ones as well as personal ones.

It is important for everybody to see us getting political and using our power to influence changes that benefit everybody.

By the way, don't take the protesting as a sign that we are all angry malcontents. Protests usually happen after many months or even years of behind-the-scenes attempts at good-faith negotiations that stagnate for political reasons.

Since, for the most part, I come from the perspective of, and share most of the opinions as, the leaders in the various segments of the movement, I attempt to represent them and explain what goes on behind the scenes and why any of it matters. There are other writers around the country doing this, but not many. Even though the Times Union has been running this column for more than two years, it is still groundbreaking every time.

Michael Volkman is a Capital Region resident and writer.

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Woman accused of fatally shooting sons who had 'agonizing' and incurable disease

By MIKE MORRIS
Atlanta Journal-Constitution Staff Writer

Michael Randy Scott and Andy Byron Scott watched the slow, miserable death of their father from Huntington's disease, and they were dying from it as well.

"My father died from it -- a long, agonizing death, years and years of just sitting in the bed dying, and they were doing it, too," said their younger brother, James Scott, whose own Huntington's disease has not advanced as far.

Early Sunday morning, Randy -- as his family called him -- and Andy Scott died, not from Huntington's but from gunshots police say were fired by their 63-year-old mother. Carol Carr of Hampton is being held in the Spalding County Jail on two counts of malice murder and could face additional charges, said Griffin Police Sgt. James Landham. Carr is likely to appear in court early this week to hear the charges against her.

Landham said that during a Saturday night visit with her sons at a Griffin nursing home, Carr shot them. She then went to the nursing home lobby and waited for police.

Randy Scott, 42, and Andy Scott, 41, who shared a room at the nursing home, were taken to different hospitals. They died early Sunday within one minute of each other, Landham said. Both were shot in the neck and head area.

"They were in the last stages of [Huntington's disease], and there's no cure for it," said James Scott, 38, the youngest of the three Scott sons, who lives with his mother and stepfather on a country road in northern Spalding County. So far, his symptoms from the disease are fairly mild -- some shaking, some discomfort.

Huntington's robs physical and mental ability as it progresses, ultimately leaving those with the disease unable to care for themselves. Symptoms typically begin to appear between ages 30 and 45.

The disease has no effective treatment. An estimated 250,000 Americans have Huntington's or are at risk of inheriting it from a parent.

For years, the Scott boys watched their father, Hoyt Scott, deteriorate. He got sick in 1976, went into a nursing home in 1983 and died in 1995. In the end, he couldn't walk, talk, leave his bed.

"It was terrible," James Scott said. "How he kept living like that, I don't know. It was agonizing."

The brothers decided they didn't want to go the same way, said James Scott, diagnosed with the disease in the mid-1990s.

"We all went to probate court in Clayton County back in 1995, and we all signed living wills saying if we got in my daddy's shape, then we didn't want to live anymore, not to try to keep us alive in any way," he said.

He said his brothers had been at SunBridge Care and Rehabilitation for Griffin about four months. The older had lived in nursing homes for about 10 years, the younger for four years.

"Andy, he didn't get the disease until later on, but he advanced in it a lot faster," James Scott said. "He couldn't do anything but sit in bed. He couldn't move, couldn't stand up, couldn't talk."

Carr, who once worked for BellSouth and remarried after his father's death, has been on medical disability since a back injury in 1981, said her youngest son.

Landham, of the Griffin police, said Carr went to SunBridge around 8 p.m. Saturday to visit her sons, as she did several times a week.

About 9:20, she shot the two men with a small-caliber handgun, Landham said.

Chuck Brown, the nursing home's administrator, said Carr "absolutely did not" give any indication when she arrived for her final visit on Saturday that she planned to take such drastic measures.

Interviewed at home Sunday, James Scott said Carr made no mention of her plans.

He said he hadn't slept since the shooting. He has been unable to reach his mother by calling the jail.

Asked if he was angry at his mother, James Scott said: "I'm angry at everybody right now.

"We kept having problems with the nursing home, getting them to change their bed linens. We had a big fight with them two weeks ago, trying to get them to help. They left them in there soaking wet," he said. "We went down there Friday, and it was the same thing."

He said his mother "shouldn't have had to go down there every day, changing them and doing the work for the nursing home. It seemed like every time one of us went down there, one of them was just sitting there in pee."

Brown, however, disputed those claims.

He said he had talked to Carr on a regular basis, and she hadn't expressed any major concerns about the care of her sons.

Last December, the SunBridge nursing home in Griffin was cited as one of Georgia's most chronic violators of state staffing requirements.

In 2000, inspectors found that the facility placed residents in "immediate jeopardy" by, among other things, failing to properly treat bedsores. In some cases, the staff was not even aware residents suffered from the sores, inspectors said.

The federal government has imposed more than $100,000 in fines against the SunBridge-Griffin facility as a result of poor care, according to records from the Centers for Medicare and Medicaid Services.

Brown, who has been at the Griffin facility for a year, said Sunday that those staffing problems were in the past, and that the facility is now fully staffed. "We haven't had any staffing issues in a long time," he said.

Eighteen staff members were on duty at the 140-bed facility when the shooting occurred Saturday night, he said.

Brown held a meeting Sunday afternoon to discuss the shooting with residents and their family members. He also brought in grief counselors for staff and residents. "A lot of the residents didn't know what was going on, but [the counselors are] here just in case."

H. Taylor Butler, a clinical social worker with the Huntington's Disease Society of America's Center for Excellence at Emory, wishes the family had reached out for help.

The center provides support groups, nursing home placement and training to families and people with Huntington's disease.

Butler said caregivers and other family members often feel helpless and even responsible for the illness of their loved ones.

"One of the things I see is them struggling with the pain of watching someone slowly, slowly and excruciatingly die," said Butler, who runs a caregivers' support group. "It's a very difficult death to watch."

James Scott said the disease took his brothers away long before the bullets did.

"I don't think my brothers died last night," he said. "I think they died a few years ago. Their life was over then."

Staff writers Carrie Teegardin, S.A. Reid and Jenny Allen contributed to this article.

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Distraught woman cries 'I'm sorry' as she appears in court on charges of killing disabled sons

By JEFFRY SCOTT

Atlanta Journal-Constitution Staff Writer

An extremely distraught Carol Carr appeared in a Spalding County courtroom today for her first hearing on charges of killing her two sons ravaged by Huntington's disease.

Crying "I'm sorry, I'm sorry" as she was led into the courtroom, Carr, 63, needed assistance from bailiffs in getting to the witness table.

Magistrate Judge Rita Cavanaugh then recounted details of the case, including how Carr is accused of shooting both Michael Randy Scott and Andy Byron Scott once each in the head with a .25-caliber pistol.

Cavanaugh repeatedly asked Carr whether she understood what was going on. Once, in reply, Carr said no.

"I understand you're upset and what you're going through but you're going to have to control yourself. Can you do that?" Cavanaugh asked.

As Carr clutched a handkerchief, she heard the judge say she lacked the authority to consider bail. Cavanaugh set a preliminary hearing date for June 27 and said the case would be transferred to a superior court judge.

Carr's extended family, including her surviving son James, were in the courtroom for the noon hearing. She turned and faced them before leaving the courtroom, telling them, "I love you all."

Carr's lawyer, Scott Walters, was not at the hearing today.

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February 25, 2002

Governors Say Medicaid Needs More Federal Help to Control Rising Costs

By ROBERT PEAR

WASHINGTON, Feb. 24 - The nation's governors demanded today that Congress and President Bush take immediate action to slow the explosive growth of Medicaid, which they say has become unsustainable in its current form. Medicaid dominated discussions today at the winter meeting of the National Governors Association. State officials sounded a note of desperation as they sought ways to control health spending.

Governors said that Medicaid, the health insurance program for 44 million people, had been eating up all the additional revenues states had collected in recent years.

"It's a major crisis," said Gov. Paul E. Patton of Kentucky, a Democrat who is vice chairman of the governors association. "We have universal agreement that something needs to be done."

In a new policy statement, the governors said, "The current fiscal crisis for states, compounded by unsustainable growth in the Medicaid program, is creating a situation in which states are faced with either making massive cuts in programs or being forced to raise taxes significantly."

Medicaid provides coverage for low-income people, including one- fifth of all children. It helps pay for one-third of births and two-thirds of nursing home residents in the United States, and it is, after education, the largest program in most state budgets.

State revenues were stagnant or declined in many states last year. But Medicaid costs increased 11 percent, and many states reported that spending on prescription drugs, which are covered by Medicaid, rose more than 20 percent.

Today, in the second session of the four-day conference, the governors advanced numerous proposals to control Medicaid spending and pleaded with the federal government for financial help.

Congress appears likely to provide some assistance but is unlikely to make fundamental changes in the structure of Medicaid this year.

Medicaid is financed jointly by the federal government and the states. Governors want the federal government to pick up a larger share of the costs, at least for some elderly and disabled people. But federal officials are reluctant to assume more of the cost because, like state officials, they foresee rising costs as baby boomers grow older.

These are some of the governors' other proposals:

- Give states the option of providing Medicaid coverage to legal immigrants who have not become citizens.
- Allow states to charge higher co- payments for drugs and services provided to Medicaid recipients. The maximum co-payment is now $3 for a prescription drug, a doctor's visit, hospital care or other services.
- Expand Medicare coverage of home health care. That would reduce the states' liability for such care under Medicaid. The federal government pays the full cost of Medicare benefits, but an average of only 57 percent of Medicaid costs, with states responsible for the remainder.
- Increase the discounts that drug manufacturers must provide to state Medicaid programs.
- Freeze or increase federal Medicaid payments to hospitals serving large numbers of poor people. Under existing law, the payments will be cut next year.
- Eliminate cuts in Medicaid payments to public hospitals, scheduled to take effect in March. The cuts result from rules recently adopted by the Bush administration, which said states were siphoning money from the federal treasury without contributing the required amounts of state money. Gov. John Engler of Michigan, a Republican, said states were particularly concerned about 7 million elderly and disabled people eligible for both Medicaid and Medicare. This group, he said, accounts for 16 percent of Medicaid recipients, but more than 30 percent of all Medicaid spending. Many of the people with dual eligibility suffer from chronic illnesses and have incomes less than $10,000 a year. Medicaid provides them with coverage for services not covered by Medicare, including outpatient prescription drugs and lengthy stays in nursing homes, which can easily cost $40,000 a year.

The governors also called on Congress to investigate the operation of a 1984 law that regulates competition between makers of brand-name prescription drugs and lower-cost generic medicines.

A resolution adopted by the governors' Committee on Human Resources says Congress should hold hearings this year to see if the law is "contributing to the high cost of prescription drugs."

Gov. Howard Dean of Vermont, a Democrat, said brand-name drug companies were manipulating the law to prolong patent protection for their products, making it more difficult for generic drugs to enter the market.

But the new governor of New Jersey, James E. McGreevey, a Democrat, emphasized the importance of patents as an incentive for companies to conduct research and develop products based on their discoveries. "Patent protection encourages investment in intellectual property," Mr. McGreevey said. "It's essential to economic growth."

Governors today also discussed welfare policy, so they could advise Congress on revisiting a 1996 law that abolished the individual entitlement to cash assistance and gives each state a lump sum of federal money to help poor families.

Under the law, families generally cannot receive federal welfare benefits for more than five years, and adults on welfare are required to work. Wade F. Horn, an assistant secretary of health and human services, said the Bush administration saw no need to change the five-year limit but wanted to give states more freedom to decide what counts as "work activity."

"There is not a single state, to our knowledge, that has had trouble with the five-year time limit, given the fact that they are able to exempt 20 percent of their caseload from the time limit," Mr. Horn told the governors.

But Mr. Horn said the Bush administration was willing to give states more freedom to combine work with job training and education for welfare recipients.

Such combinations, he said, help poor people get jobs and move up the career ladder.

"What the administration would not support," Mr. Horn said, "is going back to a system that provides education first, and for a very, very long time, before there is any expectation of work."

Example Press Coverage of a Disability Rights Issue

Provided by Brad Williams
New York Statewide Independent Living Council
Albany, New York

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OLMSTEAD PRESS COVERAGE
February 4, 2002 – February 11, 2002

WAMC radio – NPR affiliate. Live report by Karen DeWitt. The story ran at different time slots on Wednesday, February 6th through Saturday, February 9th.

WNYT television – NBC affiliate. Evening news. February 6, 2002.

Reporter: "Today, seniors and the physically challenged blocked the elevator entrances by sitting on the floor of the Corning Tower and marching in that area. The protestors say the State Health Department is not doing enough to help the disabled."

[Advocates march, carry posters and signs, and chant, "Free our brothers, free our sisters, free our people now!"]

WRGB television – CBS affiliate. Evening news. February 6, 2002.

Reporter: "People with disabilities are protesting against the State Health Department in the Corning Tower. They say the health department has not done enough to implement the Supreme Court's Olmstead decision."

[Advocates march, carry posters and signs, and chant, "Hey-hey, ho-ho, nursing homes have got to go!" New York State Troopers guard the doors to Corning Tower.]

Interview, Chris Hildebrant, Rochester ADAPT: "We are here today because Governor Pataki and the Health Department have refused to work with us. They refuse to move forward in implementing 'Olmstead.' It's a Supreme Court decision from 1999 saying that people with disabilities have the right to live independently in the community and not be warehoused in institutions."

Reporter: "State police say the protestors stopped blocking the elevators once they arrived on the scene, but continued to voice their concerns."

WTEN television – ABC affiliate. Evening news. February 6, 2002.

Reporter: "People with disabilities want the state to implement the U.S. Supreme Court's Olmstead decision. That case urges states to come up with community-based alternatives to nursing homes for the elderly and disabled. The protestors say that Governor Pataki did not mention Olmstead at all in this year's budget."

[Advocates march, carry posters and signs, and chant, "Free our brothers, free our sisters, free our people now!"]

WNYT television – NBC affiliate. Late-night news. February 6, 2002.

Reporter: "Disabled people protested today to place people in community settings instead of institutions. They blocked the entrance to elevators to the tower as police and other security personnel looked on. They have since left the building."

[Advocates chant by the escalators, then march with signs outside entryway.]

WXXA television – FOX affiliate. Late-night news. February 6, 2002.

Reporter: "Hundreds of disabled people stormed Albany's Corning Tower in protest. Building security reacts by shutting down elevators and escalators in some parts of the building."

"Disabled rights groups from all over the state filling the concourse in protest, demanding a meeting with the board of health about alternatives to nursing homes. Escalators and elevators were shut down when things heated up and protestors tried to get to the office of the Governor's chief health aide."

[Advocates march, carry posters and signs, and chant outside of entryway.]

Interview, Mel Tanzman: "I wouldn't want to live in a nursing home for the rest of my life. It's like going to prison with no bail – no parole."

Reporter: "Protestors say they'll stay at the Corning Tower through the night hoping to get what they want."

[Advocates chant by the escalators.]

WTEN television – ABC affiliate. Late-night news. February 6, 2002.

Reporter: "Protestors in Corning Tower, blocking the escalators and elevators. Tonight, they staged a sit-in inside the Capitol. The group says the state isn't doing enough to help the disabled. The Governor's spokesperson says the new budget contains hundreds of millions of new dollars for the disabled."

"About a hundred elderly and disabled people blocked the elevators as part of their protest against the State Health Department. They say the state isn't doing enough to keep seniors and the disabled out of institutions. A recent Supreme Court decision calls for the disabled to be placed in community settings, whenever possible."

[Advocates march, carry posters and signs, and chant, "Hey-hey, ho-ho, nursing homes have got to go!" New York State Troopers guard the doors to Corning Tower.]

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The Disabled Rally at Capitol for Increased Independence

By WILLIAM F. HAMMOND Jr.
Gazette Reporter

ALBANY – (February 7, 2002) Disabled rights protesters clogged the entrance to the Corning Tower for several hours Wednesday afternoon, demanding that the Pataki administration do more to transfer disabled people from institutions into the community.

The roughly 200 demonstrators - many of them in wheelchairs - swarmed past security guards on the tower's concourse level at about 2:45 p.m., surrounded the elevators and refused orders from the state police to leave. They chanted "Our homes, not nursing homes!" and other slogans, some of them using sign language.

The demonstration moved to the Capitol building in the early evening, and some participants said they planned to stay overnight, if necessary, to win a meeting with someone in the governor's office.

The protesters were pushing the Health Department - which is based in the Corning Tower - to speed its implementation of the Supreme Court's "Olmstead" decision of 1999. That ruling held that the Americans with Disabilities Act requires states, where possible, to help disabled people live in ordinary houses and apartments rather than institutions.

Activists said they grew impatient with the Pataki administration after more than a year's worth of meetings with state officials produced few signs of progress.

"In 1999, the Supreme Court said people need to be free," said Scott Smith, a protester from Rockland County. "And since that time the state of New York has done nothing to make that happen."

Health Department spokesman John Signor said the protesters' criticisms were misplaced.

"New York state spends more to help people stay in their homes than any other state in the nation - more than $5 billion," Signor said.

He noted that Gov. George Pataki's recently adopted health-care legislation directs hundreds of millions of dollars to improve pay for personal care workers who serve the disabled. As of next year, the same law will allow disabled people to continue their government-funded Medicaid coverage while making up to $45,000 per year at a job.

But Signor declined to discuss what more the administration would do to respond to the Olmstead decision.

Bruce Darling of Adapt, the disabled rights group that organized Wednesday's demonstration, said the administration should immediately apply for a federal waiver that would allow it to spend Medicaid money on community-based services for the disabled.

Activists had also asked officials to commit to deinstitutionalizing 1 percent of the state's 130,000 nursing home residents as part of this year's budget proposal, but they failed to do so.

"At a minimum, we want [Health Commissioner Antonia Novello] to meet with us to discuss this," Darling said. "This is ridiculous."

Protester Linda Ostertag, who has multiple sclerosis, said she spent "five months, 10 days and two hours" in a Rochester-area nursing home.

Ostertag said she managed to find an apartment of her own, where she lives with the help of around-the-clock attendants.

"My mission is to get everybody out that I can," she said.

"When you're in a nursing home, you're just waiting for God," Ostertag said. "When you're out on your own and running your life, you can have some self-respect."

Assemblyman Kevin Cahill, D-Kingston, who chairs a task force on the disabled, said he sympathized with the protesters' complaints.

"It's not a matter of opinion that the state has not complied with Olmstead," Cahill said. "It is a matter of fact."

Cahill said his task force asked state agencies last year to explain how they would implement the court ruling, and only the Education Department had a detailed plan.

Cahill said he is drafting legislation that would direct all state agencies to comply with the court's ruling.

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Advocates of Disabled Rally in Support of Olmstead Law

By James V. Franco
The Record (Front Page)
February 07, 2002

Photo by Jim Franco. Bob Kafka, of the advocacy group ADAPT, protests at the Corning Tower lobby in Albany Wednesday.

ALBANY - Unhappy state workers had to trudge down flights of stairs to get out of the Corning Tower, Wednesday, as a protest staged by scores of disabled and advocates for the disabled shut down the elevators.

Protesters, carrying signs, singing and chanting, called for the state to initiate the Olmstead decision, a federal law that allows people to spend Medicaid and other health money on more integrated community-based programs rather than nursing home facilities.

After nearly two hours of picketing and passing out literature, and with some protesters already having made their way to the upper floors of the Corning Tower, where the Department of Health offices are located before the elevators were shut down, officials at the DOH did agree to meet with protesters.

The outcome of the meeting was not known last night.

About 20 percent of the state's 130,000 nursing home residents are not elderly, said advocates, but young disabled persons who need assistance. Senior groups are also in favor of Olmstead, however.

"We are thrilled to be part of what we believe is a historic coalition between senior and disability groups to implement the Olmstead decision," said Greg Olsen, director of the state Coalition for the Aging.

The 1999 Olmstead U.S. Supreme Court decision would allow Medicaid and other types of funding to follow a person, if the person chooses, rather than automatically be spent to fill a bed in a nursing home facility.

"There is not enough money going into the community based programs," said Denise A. Figueroa, executive director of the Troy-based Independent Living Center of the Hudson Valley, Inc. "There is not a cost factor involved, but we have institutions built and beds have to be filled."

ADAPT, an advocacy group from Rochester who organizes the protest, wants to see the state implement a plan to "allow people with disabilities and elderly persons to live in the most integrated setting" as defined in the Olmstead decision.

Specifically, the groups criticized the state for not initiating any planning process despite the fact $50,000 has been allocated and for not developing a Medicaid waiver plan.

In addition, they want to work with the DOH to identify 1 percent of the population and transition them into a more integrated setting and expand existing community based programs and

"Clearly, New York state does not care about people with disabilities and elderly people who want to get out or stay out of nursing homes," said Bruce Darling, an ADAPT organizer. "The state should not be taking people's freedom away just because they had an accident, survived a crime, have a disability or simply get older."

Community-based programs offer those receiving the assistance a number of advantages, say advocates.

For example, Lisa Tarricone tore her rotator cuff a few years after suffering a debilitating mountain climbing accident that confined her to a wheel chair. Her insurance company refused to pay for a home assistant for three or four hours a day until she recovered, but, she said, they were willing to pay to send her to a nursing home for three months.

A working journalist in White Planes, she said she could not afford to miss three months of work. The battle with the insurance company is still going on, she said.

"They just assumed I could take three months off and go into a nursing home," she said. "It's a violation of my civil rights ... and they pretty much said I am not a contributing member of society."

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Local Protesters Shut State Health Dept.

By Yancey Roy
Democrat and Chronicle

(February 7, 2002) — About 200 protesters, many from a Rochester group, shut down the state Health Department building Wednesday to try to force the Pataki administration to move disabled people out of institutions and into apartments and homes.

Chanting and carrying signs that read, "New York State doesn't care," the protesters rushed a bank of elevators in the Corning Tower near the Capitol. That caused state troopers and security guards to close elevators and send state workers home early.

Most of the demonstrators were from ADAPT, a Rochester-based disability-rights group. They had intended to ride elevators up to the offices of Health Commissioner Antonia Novello. But security personnel turned off the elevators before protesters could board. The confrontation grew tense at one point, when protesters moved their wheelchairs in front of escalators as workers tried to exit. One worker was slightly injured when she fell during the standoff.

The activists said Gov. George Pataki's administration has promised for more than a year to put more money behind a program to get disabled people out of nursing homes.

Activists want 1 percent, or about 1,300, of disabled people moved into the community. The cost would be about $7 million, "a pittance," said ADAPT spokesman Bruce Darling.

John Signor, spokesman for Novello, said, "It's unfortunate they've resorted to such unproductive tactics." He said the state spends about $5 billion to provide in-home care to the handicapped, more than any other state.

Protest Closes Health Department
From wire service reports
Binghamton Press & Sun-Bulletin

ALBANY (February 7, 2002) – Protestors shut down the state Health Department building Wednesday to try to force the Pataki administration to do more to move disabled people out of institutions and into apartments and homes.

Chanting and carrying signs that read, "New York State DOESN'T Care," about 200 protestors rushed a bank of elevators in the Corning Tower near the Capitol, forcing state troopers and security guards to shut down the elevators and send state workers home early. Most of the demonstrators were from ADAPT, a Rochester-based disability rights group.

The activists said Gov. George E. Pataki's administration has promised for more than a year to put more money behind a program to get disabled people out of nursing homes. But so far the administration hasn't followed through, they said.

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Protest Wraps Up with Vow to Help
By JAMES M. ODATO, Capitol bureau

Times Union
Friday, February 8, 2002

After Capitol rally by advocates of the disabled leads to arrests, lawmaker promises change.

ALBANY - About 200 advocates of disabled New Yorkers, eight of whom were arrested for trespass in the Capitol on Wednesday, left Albany with the promise by at least one legislator to introduce a bill aimed at providing greater state assistance for independent living.

The group, which protested Wednesday in Corning Tower, home of the Department of Health, and later in the Empire State Plaza Concourse and Capitol, left the state buildings late Wednesday after their leaders were arrested by State Police.

Eight people, including four in wheelchairs, were charged with trespass after they refused to leave the War Room outside the governor's office after closing hours, police said. They were ordered to appear in City Court Feb. 21.

Members of the group met Thursday with the staff of Assemblyman Kevin Cahill, D-Kingston, who heads the People With Disabilities Task Force. In response to their complaint that the Health Department hasn't done enough to help elderly and disabled people integrate into mainstream society and stay out of nursing homes, Cahill said he will introduce a bill within a week to require the state to comply with terms of the U.S. Supreme Court's Olmstead decision, in particular to develop a master plan for services for the disabled.

John Signor, a Health Department spokesman, said recent health care legislation provides more funds for personal care workers and gives disabled people the opportunity to buy into Medicaid insurance so that they can continue working. However, some provisions of the health financing bill don't take effect until 2003.

The department, he said, is taking such steps as working with hospitals to make sure they don't discharge people to nursing homes if alternatives are available.

State officials also maintained that reports stating that Corning Tower or agencies in the building were closed Wednesday were incorrect. Sherry Halbrook, a spokeswoman for the Public Employees Federation, said none of the PEF employees polled about the demonstration reported a building closure or early departure. "Some people had to use alternate routes to enter or exit the building but nobody was sent home," she said.

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Disabled Activists Arrested at Protest

By William F. Hammond, Jr., Gazette Reporter

The Daily Gazette

"We didn't get a meeting with the administration, but we're extremely happy. We believe the action generated enough awareness of the issue." Bruce Darling, Protest organizer.

ALBANY (February 8, 2002) – Eight disabled rights activists who staged a sit-in outside the governor's office were arrested and charged with trespassing Wednesday night.

"They were asked to leave the premises, and they refused, so they were removed," said Sgt. Glenn Miner, a spokesman for the state police.

The activists were pushing for state officials to house more elderly and disabled people in ordinary houses and apartments rather than nursing homes. They had declared they would stay in a waiting area on the second floor of Capitol until someone in the governor's office agreed to meet with them.

Earlier the same day, hundreds of like-minded protesters had clogged the entrance to the Empire State Plaza's Corning Tower, which houses the headquarters of the state Health Department.

Security guards set the elevators so they no longer stopped on the concourse level, preventing demonstrators from reaching the Health Department offices. Officials denied reports that the building closed early for the day, explaining that employees simply used entrances on the plaza level, on floor above the protest.

The eight protesters at the Capitol were escorted out by state police at about 11:30 p.m., Miner said. They were charged with trespassing, a violation, and given tickets requiring them to appear in Albany City Court on Thursday morning.

Protest organizer Bruce Darling said the judge took no action on their cases, but told them to return on Feb. 21.

"We didn't get a meeting with the administration, but we're extremely happy," Darling said. "We believe the action generated enough awareness of the issue."

The protesters – mostly members of the group ADAPT – argue that New York must do more to comply with the Supreme Court's 1999 "Olmstead" decision. The ruling generally requires states to help disabled people live in the community, where possible, instead of placing them in nursing homes. Activists say the state is dragging its feet on implementing this policy.

"We jump-started the process," he said. "No one was aware the state was not moving forward with this. People are now aware."

Health Department spokesman John Signor said New York already does more to keep the elderly and disabled in the community than any other state, spending $5 billion per year on this effort.

He also disputed the claim that officials refused to give then protesters an audience.

"We did schedule a meeting and they declined the meeting," Signor said.

He said department officials also discussed Olmstead implementation during "a very productive" meeting with activists last week.

But Darling, who attended that earlier session, called it a "joke."

The people arrested, in addition to Darling, were: Nadina LaSpina of New York City, Larry Fein of Buffalo, Ann Kaplow of Rochester, Debbie Bonomo of Rochester, Chris Hilderbrant of Rochester,, Dina Niedelman of New York City, and Eileen "Spitfire" Sabel of Philadelphia.

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Protesters Disrupt Governor's News Conference
Democrat and Chronicle

ROCHESTER (February 8, 2002) — About 25 people disrupted Gov. George Pataki's news conference in Henrietta on Friday. The disability rights group ADAPT of Rochester demanded that the governor do more to assist senior citizens and those with disabilities to live at home instead of in nursing homes.

Pataki, who was in town to discuss Elderly Pharmaceutical Insurance Coverage, which helps senior pay for prescription drugs, continued his conference after a brief interruption.

Some of Friday's protesters, including Bruce Darling of Hilton, were arrested Tuesday in Albany at the state Department of Health building when they demanded a meeting with one of the governor's top health care policymakers.

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Protesters Rock Pataki Visit

By Matt Leingang
Democrat and Chronicle

Photo by Will Yurman. Susan Norwood was among demonstrators on Friday who protested outside Henrietta's Don W. Cook Senior Center, where Gov. Pataki spoke.

ROCHESTER (February 9, 2002) — Protesters disrupted Gov. George Pataki's visit to Henrietta yesterday, charging that his administration is not doing enough to move disabled people out of institutions and into apartments and homes.

Carrying signs and chanting "Pataki doesn't care," about 25 protesters greeted the governor as he arrived around noon at the Don W. Cook Senior Center.

Once inside, Pataki started a news conference to talk about the state's Elderly Pharmaceutical Insurance Coverage program, which helps senior citizens pay for prescription drugs.

About 250,000 New York residents are now enrolled in the program -- the most ever.

But Bruce Darling of Hilton, who is part of a Rochester-based disability-rights group called ADAPT, stood up and began talking over Pataki, saying the governor is dragging his feet when it comes to getting the disabled out of nursing homes.

Darling was upset that he and others weren't able to get a meeting in Albany with the governor's health policy team on Wednesday. He recounted how he was arrested when he stormed the state Health Department building.

"I can see why," Pataki quipped.

But the exchange never got nasty. The governor kept his cool as he calmly defended his administration. The state spends about $5 billion to provide in-home care to the handicapped, more than any other state, he said.

Pataki's representatives then pulled Darling aside.

"They promised me a meeting," Darling, 37, said later. "I'm hoping (Pataki) stays good to his word."

A recent U.S. Supreme Court decision said disabled people had a right to receive state services in an integrated setting, which activists interpret as private homes or apartments.

Activists want 1 percent of disabled people -- or about 1,300 statewide -- moved into the community, and they want the state to apply for a Medicaid waiver from the federal government to help. The cost would be about $7 million, Darling said.

The protesters, many of whom were in wheelchairs, again jeered Pataki as he left the building and entered an awaiting van.

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State Slow to Help Disabled, Protestors Complain

By James Andrew Schlett, Staff Writer
The Legislative Gazette
February 11, 2002

Photo by James Andrew Schlett. A state trooper blocks an entrance to the Corning Tower at Empire Plaza as about 200 people inside and outside the building protest what they consider the state's noncompliance to federal disability laws.

In World War II, the maneuver was called blitzkrieg, a lightning-fast attack used to break through the front line. Going down the Concourse of Empire State Plaza in two columns and then advancing on the Corning Office Tower with the speed of Panzer tanks last Wednesday, about 200 protesters, many of whom were in wheelchairs, conducted their blitzkrieg outside state offices to protest what they consider New York's failure to comply federal disability laws.

Storming past security guards and rolling over rope gates, the protesters filled and occupied the elevator hallways at the building's ground floor, where they remained for more than three hours.

At the 13th floor of the building is the state Department of Health, which the protest groups, ADAPT the Coalition to Implement Olmstead in New York and others, say has discriminated against disabled individuals by not helping them get out of institutions and into community settings.

Within minutes of the initial protest siege, state troopers and corrections officers blocked the tower's main doors, allowing workers and protesters out but not letting them in. The protesters left outside picketed while the others inside chanted, "Our homes not nursing homes."

No one was arrested at the Corning Tower protest, but eight were arrested for trespassing at another sit-in at the Capitol Building that lasted until about midnight, police said. No one was hurt.

"We went for the elevators. We're taking up space until we get what we want," said protester Chris Hilderbrant.

The protest, the second conducted at the tower by the groups in six months, had roots in the United States Supreme Court's 1999 Olmstead decision. The court ruling says that unjust isolation of disabled individuals is discrimination and that states must aid them in living in the most integrated settings. Despite an executive order by President George W. Bush issued last June ordering state officials to place qualified individuals with disabilities into community settings, disability advocates say they continue to find people in nursing homes, developmental disability centers and psychiatric centers living in these institutions against their will.

With the protesters blocking the elevators, workers trickled down the escalator to the ground level. Although there was one brief skirmish between a worker and protester in a wheelchair near the escalator, the protesters stuck to the elevator hallways as though they were waiting for the ride up that never came. They were hoping to meet with Antonia C. Novello, the Health Department's commissioner, said Bruce Darling, the executive director of NYSILC and a protest organizer.

"This is absolute discrimination," Darling said of the state's alleged noncompliance to Olmstead. "If we [unjustly institutionalized] people of color, we would ask ourselves what ... are we doing."

Darling said many people in state institutions do not know they can live in the community under the American Disabilities Act. Even those who do know, he said, meet strong resistance from institution personnel and have to file civil complaints to the federal government to move into the community.

"What is problematic [with Olmstead] is identifying who those people are," said Gregory Jones, the deputy director advocate for the Office of Advocate for Persons with Disabilities. "There are those cases where people fall through the cracks," but New York is leading in Olmstead compliance "to the very top," he added.
Since 1999, 37 civil rights complaints concerning Olmstead have been filed, said Robinsue Frohboese, the principal director for the office of Civil Services in Washington, D.C. The number of complaints, she said, is about the national average.

The protest groups demanded the state adopt an Olmstead planning process that would make these moves easier for people with disabilities and remove the need for the civil complaints. The groups also demand a Medicaid waiver that would transfer funds wit the individual from the institutions to the community program. While waivers are in place for brain trauma victims, the advocates said such waivers should also apply to people with multiple sclerosis and cerebral palsy. Legislators are divided on the issue, with some saying the state is in Olmstead compliance and others saying it is not.

"We are fighting a new civil war," ADAPT organizer Bob Kafka said at a rally shortly before the siege on the Corning Office Tower. "[It is a war] between state rights and the federal government."

The groups have some support in Albany.

"It's time New York State stepped up to the place and comply," said Assemblyman Kevin Cahill, D-Kingston, chairman of the Task Force on People with Disabilities. Cahill announced at a press conference a day before the protest that he is drafting legislation that would require the state to comply with these laws. The bill is weeks away from completion, he said.

Unable to meet with Novello, advocacy group representatives said they arranged a meeting with David Wollner, Gov. George E. Pataki's assistant director of state operations-health and Medicaid. When Wollner did not show for the meeting, the protesters moved the rally from the Corning Office Tower to the Capitol Building.

Additional Press:

New York StateWide Senior Action Council
Press Release
Thursday. February 7, 2002

StateWide Senior Action Council to Join Disability Group Protest Against Health Department

New York State Wide Senior Action Council said today that it is joining disability groups in the effort to force a more proactive state policy to fund community alternatives to nursing homes. "We support their protest yesterday which is a reflection of the fact that the New York State Department of Health leadership does not take consumer organizations seriously enough on this matter, said Michael Burgess, Executive Director. "I think that if things don't change and they refuse to take this seriously, the demonstrations will continue with seniors joining the disabled in larger numbers."

StateWide and the disability groups want the state to make a more active effort to implement the US Supreme Court's Olmstead decision which says that institutionalization constitutes discriminatory segregation and that citizens have the right to first have community based alternatives to nursing homes and other institutions. StateWide says it will join disability groups in filing civil rights complaints against hospitals and nursing homes that keep older people against their will. "We have referred to the Attorney General the cases of two seniors who were warehoused in hospitals for several months and the hospitals sought guardianship proceedings against them and billed them tens of thousands of dollars," Burgess added.

State Health Commissioner Antonio Novello had agreed to meet with its leadership after a similar protest rally of 100 seniors at the Health Department in November 2000. However, the meeting which was set up five months later was cancelled and never re-scheduled. StateWide has also invited Novello on several occasions to speak to its annual conference and she has never been available.

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February 4, 2002
Paid Advertisement
(Page 1)
THE DISABILITY
AND SENIOR COMMUNITIES

ADAPT New York City, ADAPT Rochester, Association of Independent Living Centers in New York, Brain Injury Association of New York State, Coalition of New York State Alzheimer's Association Chapters, Coalition On Independent Living, Disabled In Action, Eastern Paralyzed Veterans Association, Housing Works, New York Association of Psychiatric Rehabilitation Services, New York State Coalition for the Aging, New York State Independent Living Council, and the New York State Wide Senior Action Council.

UNITED IN SUPPORT OF OLMSTEAD IMPLEMENTATION IN NEW YORK STATE

What does new york state need to do?

- **Sign an Executive Order or Pass Legislation to Support Olmstead Implementation.** Require all state disability and senior service agencies to develop coordinated plans and timetables to comply with the Americans with Disabilities Act (ADA) requirement that people with disabilities and older adults be served in the most integrated setting appropriate to their needs with the input of people with disabilities and seniors.
- **Identify People with Disabilities and Seniors Who Can Transition into the Community.** Ask each state disability service agency to identify a process whereby they can identify the number of people with disabilities and seniors in their systems that can transition into a more integrated setting.

- **Transition at Least 1% of the Target Population into a More-Integrated Setting.** Demonstrate a commitment to the process by achieving reasonable and immediate progress.
- **Expand Community-Based Service Options for Seniors and People with Disabilities to Prevent Them from Being Institutionalized.**
- **Implement a Medicaid Waiver Program.**
- **Expand the Consumer Directed Personal Assistance Program.**
- **Apply for Federal Real Choice Systems Change and Nursing Home Transition Grants.** NYS DOH should reapply for the $40 million dollars available in Federal "real choice" and $15 million in "transition" grants. The proposal should include the involvement of people with disabilities and older adults and look to address any or all of the items listed above.

(Page 2)
NEW YORK STATE
MUST COMPLY WITH
OLMSTEAD

The White House
President George W. Bush

For Immediate Release
Office of the Press Secretary
June 19, 2001
Executive Order
Community-based Alternatives for Individuals with Disabilities

By the authority vested in me as President by the Constitution and the laws of the United States of America, and in order to place qualified individuals with disabilities in community settings whenever appropriate, it is hereby ordered as follows:

Section 1. Policy. This order is issued consistent with the following findings and principles:

(a) The United States is committed to community-based alternatives for individuals with disabilities and recognizes that such services advance the best interests of Americans.
(b) The United States seeks to ensure that America's community-based programs effectively foster independence and participation in the community for Americans with disabilities.
(c) Unjustified isolation or segregation of qualified individuals with disabilities through institutionalization is a form of disability-based discrimination prohibited by Title II of

the Americans With Disabilities Act of 1990 (ADA), 42 U.S.C. 12101 et. seq. States must avoid disability-based discrimination unless doing so would fundamentally alter the nature of the service, program, or activity provided by the State.

(d) In Olmstead v. L.C., 527 U.S. 581 (1999) (the "Olmstead decision"), the Supreme Court construed Title II of the ADA to require States to place qualified individuals with mental disabilities in community settings, rather than in institutions, whenever treatment professionals determine that such placement is appropriate, the affected persons do not oppose such placement, and the State can reasonably accommodate the placement, taking into account the resources available to the State and the needs of others with disabilities.

(e) The Federal Government must assist States and localities to implement swiftly the Olmstead decision, so as to help ensure that all Americans have the opportunity to live close to their families and friends, to live more independently, to engage in productive employment, and to participate in community life.

Sec. 2. Swift Implementation of the Olmstead Decision: Agency Responsibilities.

(a) The Attorney General, the Secretaries of Health and Human Services, Education, Labor, and Housing and Urban Development, and the Commissioner of the Social Security Administration shall work cooperatively to ensure that the Olmstead decision is implemented in a timely manner. Specifically, the designated agencies should work with States to help them assess their compliance with the Olmstead decision and the ADA in providing services to qualified individuals with disabilities in community-based settings, as long as such services are appropriate to the needs of those individuals. These agencies should provide technical guidance and work cooperatively with States to achieve the goals of Title II of the ADA, particularly where States have chosen to develop comprehensive, effectively working plans to provide services to qualified individuals with disabilities in the most integrated settings. These agencies should also ensure that existing Federal resources are used in the most effective manner to support the goals of the ADA. The Secretary of Health and Human Services shall take the lead in coordinating these efforts.

(b) The Attorney General, the Secretaries of Health and Human Services, Education, Labor, and Housing and Urban Development, and the Commissioner of the Social Security Administration shall evaluate the policies, programs, statutes, and regulations of their respective agencies to determine whether any should be revised or modified to improve the availability of community-based services for qualified individuals with disabilities. The review shall focus on identifying affected populations, improving the flow of information about supports in the community, and removing barriers that impede opportunities for community placement. The review should ensure the involvement of consumers, advocacy organizations, providers, and relevant agency representatives. Each agency head should report to the President, through the Secretary of Health and Human Services, with the results of their evaluation within 120 days.

(c) The Attorney General and the Secretary of Health and Human Services shall fully enforce Title II of the ADA, including investigating and resolving complaints filed on behalf of individuals who allege that they have been the victims of unjustified institutionalization. Whenever possible, the Department of Justice and the Department of Health and Human Services should work cooperatively with States to resolve these complaints, and should use alternative dispute resolution to bring these complaints to a quick and constructive resolution.

(d) The agency actions directed by this order shall be done consistent with this Administration's budget.

Sec. 3. Judicial Review.

Nothing in this order shall affect any otherwise available judicial review of agency action. This order is intended only to improve the internal management of the Federal Government and does not create any right or benefit, substantive or procedural, enforceable at law or equity by a party against the United States, its agencies or instrumentalities, its officers or employees, or any other person.

GEORGE W. BUSH
THE WHITE HOUSE
June 18, 2001.

GOVERNOR PATAKI
MUST FOLLOW THE LEAD OF
PRESIDENT BUSH ON OLMSTEAD!

(Page 3)
REAL LIFE EXAMPLES...

Helen B. is a 56-year-old woman with a Bachelor's degree in Liberal Arts, with a concentration in English. She has Cerebral Palsy, visual impairments, and learning disabilities. Helen was living in her own apartment in Broome County until she was forced into a nursing home under the pretense of rehabilitation that was supposed to last for only one month. Helen desperately wanted to leave that institution and receive services in the most integrated setting- her own home. Because New York State does not have a plan in place to monitor the implementation of the Olmstead ruling, Helen was forced to remain in an institution for nearly 8 months. Helen began working with advocates so that she could exercise her rights under the Olmstead ruling and the ADA. Helen and the advocates worked hard so that Helen could leave the institution. They filed an Office of Civil Right (OCR) Complaint on Helen's behalf to bring attention to the fact that Helen was imprisoned in a nursing home because New York State had nothing in place to monitor the implementation of the Olmstead ruling. Eventually, Helen was able to leave the nursing home and relocate to Monroe County. She now lives in her own apartment, where she receives attendant services through the Consumer Directed Personal Assistance Program (CDPAP) and other services under the OMRDD Waiver. Helen immensely enjoys her freedom! She enjoys cooking, reading British Literature, and being able to do whatever she wants, when she wants. She is successfully living independently in the most integrated setting- her own apartment in the community.

WHY NEW YORK STATE

Dennis W. is a 33-year-old man, who became a quadriplegic as a result of a gunshot. Dennis was forced into an institution because he did not have the resources or information to find an accessible apartment. He was put into a nursing home against his will and forced to remain there for 5 months. The nursing home never informed him of his right to receive services in the community. He was offered a fully accessible apartment two months after entering the nursing home, but he could not accept the apartment because he was denied for traditional home care services. Dennis thought he would have to spend the rest of his life in a nursing home! Through a chance meeting, Dennis began working with advocates to secure his freedom. Advocates filed an OCR complaint on Dennis' behalf, citing the fact that Dennis was forced to remain in an institution because New York State did not have a plan in place to monitor the implementation of the Olmstead ruling. Dennis was able to eventually leave the nursing home and move into his own fully accessible apartment. He receives 24 hour per day attendant services through the CDPAP. He works part-time as a disability advocate and enjoys helping others get out of nursing homes. In addition to his part-time job, Dennis enjoys spending time with his two children, socializing with friends, and taking full advantage of his freedom!

MUST COMPLY

Alfred W. is a 30-year-old man who became a quadriplegic as a result of a spinal cord injury. He was forced into a nursing home in 1995 because of lack of accessible housing and denial of traditional home health care services. For nearly six years, Alfred sat in a nursing home because no Community Home Health Agency (CHHA) would provide him with home health care services. An advocate advised Alfred that it was his right under the Olmstead ruling to receive services in the most integrated setting. They filed an OCR complaint on Alfred's behalf against New York State because New York State does not have a plan in place to monitor the implementation of the Olmstead ruling. Through the hard work and dedication on the part of Alfred, his social worker, and advocates, Alfred was finally able to leave the nursing home. Today, he lives in his own fully accessible apartment, where he receives attendant services through the CDPAP and Service Coordination and a Self Directing Other (SDO) under the OMRDD Waiver. Alfred was the first person to receive a SDO through OMRDD. After nearly six years of imprisonment in a nursing home, Alfred is thrilled to have his own apartment. He enjoys working on his computer and has been living successfully in the community for almost a year. Alfred now acts a volunteer in helping people to get out of nursing homes.

WITH THE OLMSTEAD

Maria V. is a 65-year-old woman who has a seizure disorder, diabetes, and kidney failure. On the day of her planned discharge from the hospital, Maria fell in her hospital bathroom and broke her arm. The hospital staff insisted that Maria must go to a nursing home for rehabilitation of her broken arm. Maria vehemently opposed going to a nursing home, as she knew of many others who went to a nursing home under the pretense of rehabilitation and were forced to stay there for years. Despite the fact that the Olmstead ruling clearly indicates that individuals have the right to receive services in the most integrated setting, the hospital and CHHA insisted that Maria could not receive services at home. Among other excuses they used, they claimed that the CHA did not have enough staff to provide Maria with the coverage that she needed. Advocates filed an OCR Complaint on Maria's behalf. Almost immediately, the CHHA agreed to provide services to Maria in the community. Maria was able to return to her apartment and receive traditional home health aide services, as well as services provided through the OMRDD Waiver. Maria was lucky enough to be connected to advocates who helped her to preserve her freedom. If she didn't have that help, she would have been institutionalized at a much higher cost than the few hours of the home health care services that she receives now. Today, Maria is happily living in her own apartment with her cat. She enjoys socializing her friends and is thankful that she avoided being imprisoned in a nursing home!

U.S. SUPREME COURT DECISION!

Marie W. is a 59-year-old woman who has Multiple Sclerosis. Marie had lived in her own apartment and received traditional home health care services. When she was hospitalized for a planned surgery, the CHHA closed her case. The CHHA advised her that IF they reopened her case, they would provide her with fewer hours. Because the fewer hours did not meet her needs, Marie was forced into a nursing home. Marie began working with advocates to free her from the nursing home. Because New York State did not have a plan in place to monitor the implementation of the Olmstead ruling, CDR filed an OCR Complaint on Marie's behalf. Ultimately, the advocates were able to assist Marie in moving back to her own apartment, where she receives 24-hour per day attendant services through the CDPAS Program. Her enrollment in the CDPAS Program is also saving the state money compared to the cost of a nursing home or CHHA services. Marie loves living in her own apartment! She enjoys spending time out doors, and being able to go where she wants, when she wants to.

The State of Olmstead

Brad Williams, NYSILC Executive Director

What is the state of Olmstead in New York State? Olmstead is the 1999 U.S. Supreme Court decision that makes it an act of discrimination to institutionalize a person with a disability against their will, especially when they can live in the community with appropriate supports. It directs states to develop a comprehensive plan to ensure that people have the opportunity to live in the "most integrated setting" possible.

Advocates have gone through an arduous process with the New York State Department of Health (NYS DOH) for over a year to develop two funding opportunities that will address nursing home transition and diversion on a small-scale basis. It's a start and should be recognized. However, this effort is nowhere near the sweeping policy change needed nor the comprehensive effort required to comply with a U.S. Supreme Court decision rendered three years ago.

Based on NYS DOH figures, there are 129,762 people currently in nursing homes in New York State. Eighty-seven percent (112,531) are seniors 65 and older. Seven percent (9,027) are between the ages of 21-54, while the remaining six percent (8,204) are people 55-64. What is more disturbing: The volume of seniors currently in nursing homes, or the fact that there are 17,231 working-aged adults held against their will? I am 42 years old and I can't even fathom how I could accept living the rest of my life in a nursing home. I suspect you feel the same. The situation expands further when you consider individuals in psychiatric centers, adult homes, community residences, etc. Besides the "quality of life" argument, hmmm...I wonder what the burden is to New York State taxpayers? Yes, believe it or not, it costs less to provide services to individuals in a community-based setting as opposed to an institution.

This isn't a partisan issue. The Assembly Task Force on People with Disabilities held a hearing on Olmstead almost two years ago. Assembly

Speaker Sheldon Silver found it important enough to attend and give the opening comments. Assembly member Kevin Cahill, Chair of the Task Force, made it a priority and authored the "most-integrated setting" bill. It passed unanimously in the Assembly on June 12th. Senate Majority Leader Joseph Bruno personally introduced the bill and ushered its unanimous passage through the Senate on June 20th. At a recent ADA celebration in Plattsburgh, Assembly member Chris Ortloff spoke about his strong support of Olmstead implementation in New York State. He articulated aspects of the Court's mandate that proved he had done his homework.

Oh, yes. There is one other person who strongly supports Olmstead implementation. His name is President George W. Bush. He issued an Olmstead executive order as Governor of Texas. The President then issued a similar executive order for our entire country on June 19, 2001. He has followed through with several funding opportunities for States on the most-integrated setting issue.

What about other States? The State of Arkansas has developed a model nursing facility transition program in the meantime. The State of Missouri has passed and implemented legislation that is similar to New York's "most-integrated setting" bill. Yet, it goes even further to mandate that the money should follow the individual and their living choice. An institution should never be able to control the funding to support a person's care to the point where it eliminates personal choice. The State of Texas is committing significant state funds to match the Federal funding opportunities provided for Olmstead implementation. New York is one of about ten states that have demonstrated very little progress to date. The DOH funding opportunities in New York haven't even commenced and we're three years into the Court's decision.

Another facet to Olmstead implementation is the process available to individuals to file discrimination complaints with the Federal Office of Civil Rights (OCR) against the State of New York. These OCR complaints are a way for the individual to remedy their personal situation despite the State's lack of policy in this area. New York currently has around seventy-five OCR complaints filed against it. Unfortunately, this is the one category where New York State is an erroneous leader. In addition, the OCR complaint process is not for the weak. It is a long, emotional roller coaster ride. "The Post-Star" chronicled Betty Cranston's effort to return home to Lake Luzerne. "Newsday" is in the process of covering the same for Darlene Cruz, as she fights to go back to her home in Long Island.

So what is delaying the progress? It is now up to Governor George E. Pataki. He can demonstrate leadership on this issue and sign the "most-integrated setting" bill into law. It would establish a policy-making state council to develop and implement a comprehensive most-integrated setting plan consistent with the Olmstead U.S. Supreme Court decision.

What happens if the Governor balks at his responsibilities? The primary reason for doing so has more to do with a reality I learned in a "Sociology of Literature" class at SUNY Albany back in 1983. The professor was a brilliant woman who earned her doctorate from Columbia University and survived the ghetto in Warsaw during World War II. She also experienced post-war communist oppression and eventually had to flee the country. Periodically, students would comment on how bad it must have been to be censored and not have the right to free speech, let alone the terrible abuses and retaliation that awaited those who dared to speak their mind, not to mention being imprisoned against one's will.

The professor would listen intently with a forced smile on her face. She would confirm the obvious, but then challenge the students in return. "You know, you have your own indirect form of censorship in America." The students would look puzzled. "It is such a part of your culture that you don't even realize how much it dictates your life." Continued puzzlement. "It's the Almighty Dollar. Very little happens in this country if you don't have the money to support or pursue it. In fact, even the most amazing idea won't happen if you can't market or sell it." The shameless truth, "Your freedom is limited by your ability to buy and sell." Ouch.

The Governor needs to rise above the impact and influence money has on our political process and direct this State to comply with a U.S. Supreme Court decision. He needs to value humans over money. Otherwise, he will look no different than a Southern Governor in the late 1950's - early 1960's. Or maybe it's more appropriate to say that he would look like Tommy Olmstead, a man of dubious distinction, who was the head of human services for the State of Georgia. Instead of Olmstead implementation, we could have Pataki implementation someday. Why? Remember the OCR complaints? They are just the tip of the ice berg. If Governor Pataki lets the situation unravel, he will leave citizens no other option but to sue him and the State of New York for their freedom.

Resources

Web Links

http://www.nod.org - Website of the National Organization on Disability. You can get headlines and stories from newspapers around the country related to disability here. *Click on the "news" section.*

http://www.accessiblesociety.org - The Center for an Accessible Society – a communications clearinghouse providing journalists credible information and quotable sources on national disability policy and independent living issues.

http://www.ncdj.org - National Center for Disability and Journalism. Has a useful style guide.

http://www.ruckus.org/man/media_manual.html - the Ruckus Society's (they sponsor direct action for global justice) media manual.

http://www.newsdirectory.com – News directory for all 50 states.

http://www.ilusa.com - A project of the New York State Institute on Disability, the Independent Living Center of the Hudson Valley, Inc., the Capital District Center for Independence, Inc., and Verizon. Contains, news, views, and resource information.

PowerPoint Presentation

Media Advocacy

- engages mass media with the goal of reordering public policy priorities.

- is the strategic use of mass media as a resource for advancing a social and public policy initiative.

- uses a set of techniques drawn from public relations, political campaigns, advertising, investigative journalism, and grassroots lobbying.

Larry Kirkland
Berkeley Media Studies

Media: The Key to Empowerment

"If you don't exist in the media, for all practical purposes, you don't exist."

Daniel Schorr
National Public Radio

"New words and phrases are one organic measure of change. They capture transformation of perception, and sometimes of reality itself."

Gloria Steinem

AP Stylebook

wheelchair-user People use wheelchairs for independent mobility. Do not use confined to a wheelchair, or wheelchair-bound. If a wheelchair is needed, say why.

www.aboutdisability.com/bib.html
by Anthony Tusler

The New Paradigm of Disability: A Bibliography

It has been thirty years since the beginning of the contemporary Independent Living Movement. It was a time when the previously separate groups of people with disabilities began to collectively fight for the respect, and demand the civil rights, enjoyed by mainstream America…….

Community/Culture
Family, Children, and Relationships
Identity policy/Civil Rights
Children and Young Adults
Publications
Disability Studies
History
Radio
Movies/Videos
WWW

Re/frame the debate: Changing common perception

- Words - People First Language
- Articulate paradigm shift from medical, charity and rehab models to independent living, inclusion, and empowerment models
- Images - photographs and posters
- Spokesperson(s)

Media Advocacy Timeline:

- 1975 - PL 94-142
- 1977 504 demonstrations
- 1978 - ADAPT (accessible public transit)
- 1983 Elizabeth Bouvia
- 1988 Deaf President Now; Mac & Me
- 1990 ADA; ADAPT (community-based attendant services); My Left Foot
- 1991 Bree Walker Lampley; Primetime on FC
- 1992 – Jerry's Orphans
- 1993 - TASH protest of Frontline on FC
- 1996 - Not Dead Yet
- 2000 - Nike - Dry Goat ad; King Gimp
- 2001 - FDR memorial

Re/frame the debate: Sound bites/press lines

- Not Dead Yet
- We Will Ride
- Free Our People
- Same Struggle, Different Difference
- Nothing About Us Without Us
- ALL means ALL
- Take Me to My Least Restrictive Environment
- We Are People First
- Jerry's Orphans

Tactics: The Keys to Reframing the Debate

- Op-Eds
- Public Service Announcements (PSA)
- Public Affairs/Community Affairs
- Press conferences/Media Events

Concord Monitor Thurs, August 30, 2001
Editorial: Let him speak

- *A controversial thinker deserves civil treatment in Concord.* The Governor's Commission on Disability is under attack for inviting a provocative and unpopular thinker to a Concord conference on genetics and bioethics. But such boldness is to the commission's credit. There is nothing to fear in Peter Singer's appearance but the fear of ideas....

- Consider this observation from Practical Ethics, one of Singer's two dozen books: "Killing a disabled infant is not ethically or morally equivalent to killing a person. Very often it is not wrong at all."....

- One advocacy group, called Not Dead Yet, is protesting the prospect of Singer's appearance in New Hampshire; it protested his appointment at Princeton as well. Republican gubernatorial want-to-be Bruce Keough has called on Gov. Jeanne Shaheen and the disability council to rescind the invitation....

They should not. Singer should be heard - and challenged, as he will be, by his audience and fellow speakers alike....

Op-Ed/Letter to the Editor

- Op-Ed means “Opposite the Editorial Page”
- Usually between 500 – 1000 words
- Reframes the debate
- Establishes spokesperson(s)
- Establishes organization as a “source”

Concord Monitor

No science behind Singer's Agenda

Wed. Sept. 5, 2001 **by Stephen Drake**

Letter to the editor: Your editorial on the Peter Singer controversy contains so many inaccuracies, distortions and plain muddled thinking it is hard to know where to begin. First, you suggest that Singer is "misunderstood" by the disability rights movement. This is a patronizing and unwarranted assumption. Many of us have read more of Singer's work than anyone on your editorial staff. Not Dead Yet has issued comprehensive analyses of his works that relate to disability. I have taken Singer on in an NPR show aired in Philadelphia. We understand his work and what he stands for all too well. Singer asserts that it should be legal for parents to have newborns with disabilities killed within the first 28 days after birth. A less often noted assertion of Singer's is that people with cognitive disabilities of any age should be killed by medical professionals if they don't meet Singer's criteria for personhood and if the family or legal guardian wants it done.

According to Singer, individuals who don't qualify as "persons" should be denied constitutional protections to due process and equal protection of the law. This public policy proposal would affect thousands of New Hampshire citizens with Alzheimer's, mental retardation and other cognitive disabilities.

Singer builds his case in much the same way Charles Murray and Richard Herrnstein did in The Bell Curve, a notorious bestseller that claimed to "prove" that people of African descent were intellectually inferior to Caucasians. The book was an attempt to legitimize and normalize racial inequalities. It was a political agenda masquerading as science. Singer promotes his ideas the same way. He uses disability-related research selectively, ignoring anything that interferes with his agenda. When supporting research can't be found, he resorts to unsubstantiated assertions. Given that the Monitor is likely to revisit this controversy in the future, I hope you will give disability activists at least as much respect as you have shown for Peter Singer. At least do us the courtesy of accurately recounting our perspective.

STEPHEN DRAKE Forest Park, Ill. (The writer is a research analyst for the group Not Dead Yet.)

The Concord Monitor

Nazi 'Principles'

By Tom Cagle Wed. September 5, 2001

Letter to the editor: As a board member of Not Dead Yet, I am writing to clarify some highly debatable statements in your editorial on the Peter Singer controversy. You glibly dismiss any comparisons between Singer and the ideologies that resulted in the extermination of some 250,000 people with disabilities in Germany. In fact, Holocaust scholar Michael Burleigh pointed out that Nazi propaganda - and eugenics literature predating the Nazi regime - promoted the idea of euthanasia based on both "humanitarian" principles and utilitarian ideals. Burleigh noted these are the same principles and ideals Singer uses to promote his own agenda. The fact that Singer's grandparents were victims of the Holocaust has no relevance to the issue of comparing his own ideologies with those that lead to the German extermination program of people with disabilities. But it seems fair to say Singer regards the murder of his grandparents as a greater crime than killing of people with disabilities at the hands of the Nazis. We believe the murders to be equally heinous. We remember our history, even if Michael Jenkins, Peter Singer and the Monitor editorial staff don't.

The Concord Monitor

Keep the fox out

By Gail McLeon Thursday September 6, 2001

Letter to the editor: I write concerning your stand regarding the decision by the Governor's Commission on Disability to invite Peter Singer to New Hampshire. In your editorial, you suggest it is appropriate for the commission to invite Singer to one of its events.

I would travel some distance to confront Singer concerning his viewpoints at an ethics conference or medical convention, but inviting him to address a gathering hosted by members of the disability community is a mistake. This implies acceptance and respect for his views by the disability community itself. Singer advocates legal extermination of people with advanced Alzheimer's, profound mental retardation and other cognitive disabilities. Singer promotes the idea these are "non-people" and the idea of extermination is good public policy. Would you give your support to a government-sponsored holocaust remembrance event that invited members of

Aryan Nation to defend actions of the Nazis against the Jewish people? Since you find Singer worthy of respect and civility, I shall expect to see a future editorial calling on the Human Rights Commission to host exactly this sort of an event. Seems a bit like asking the fox to address a gathering in the hen house.

PRESS KITS

- Press release or media advisory (5 Ws; inverted pyramid, contact person)
- Fact sheet and chronology
- Quotes or comments by experts (our experts)
- Press clippings from mainstream & disability press
- Statements, speeches or testimony
- Biography on spokesperson(s)
- Background information about key organizations

Hooray for Hollywood?

Write to:
1) Executive Producers listed at beginning of the show.

2) Send letter to studio/production company listed at end of show.

3) Send a copy to network head & "broadcast standards dept."

- Stuart Bloomberg, Co-Chairman
ABC Entertainment
500 S. Buena Vista Street
Burbank, CA 91521
www.abc.com

- Leslie Moonves, President
CBS Entertainment
7800 Beverly Boulevard
Los Angeles, CA 90036
www.cbs.com

- Sandy Grushow, Chairman
Fox TV Entertainment
10201 W. Pico Boulevard
Los Angeles, CA 90035
www.fox.com

- Jeff Zucker, President
NBC Entertainment
3000 W. Alameda Avenue
Burbank, CA 91523-0001
www.nbc.com

- Dean Valentine, President/
UPN
11800 Wilshire Boulevard
Los Angeles, CA 90025
www.upn.com

- Susanne Daniels & Jordan Levin
Co-Presidents, Entertainment
WB Television Network
4000 Warner Blvd., Bldg. 34-R
Burbank, CA 91522
www.thewb.com

Media Advocacy Summary

- Build relationships with the press
- Re/frame the debate
- Identify spokesperson(s)
- Establish organization as a news "source"
- Find the news "hook"
- Be an aglet!
- Be persistent – don't give up!

IL Net Presents

Making News: How the IL Movement Cultivates Media Relationships

October 16-18, 2002

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